

alzheimer's  association®

Greater Indiana Chapter

CAREGIVER'S GUIDE

INFORMATION AND RESOURCES ABOUT ALZHEIMER'S DISEASE
AND OTHER DEMENTIAS



DIGITAL EDITION

For a free, printed publication of this guide, call 317.575.9620



Dear Friend,

This Caregiver's Guide is a comprehensive resource for individuals and family members caring for someone with Alzheimer's disease or other dementia.

The information and suggestions presented in this guide have been compiled from the existing body of literature on caring for persons with dementia from professional service providers and family caregivers. Not all suggestions will be appropriate for every person with Alzheimer's disease nor pertain to every stage of a person's illness. These pages contain a great deal of information, so we suggest you pace your reading. Start with sections that address your immediate questions and concerns. Reflect upon what you've read, and use the space provided to jot down notes and ideas that work for you.

The Alzheimer's Association stands ready to help you, your family, and loved one during the journey. Our 24/7 Helpline, free education classes, support groups, care consultation services, online support, and MedicAlert® + Alzheimer's Association Safe Return® exist to provide you and your family member with the tools and resources necessary to successfully manage Alzheimer's disease and other dementias.

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SECTION 1:

UNDERSTANDING ALZHEIMER'S DISEASE

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Understanding Dementia

Dementia is not a disease but a symptom of certain diseases or conditions. It is a global—or umbrella—term that refers to a group of symptoms, such as progressive memory loss, confusion, changes in personality, mood and behavior, a decline in problem-solving and judgment skills, and language deficits.

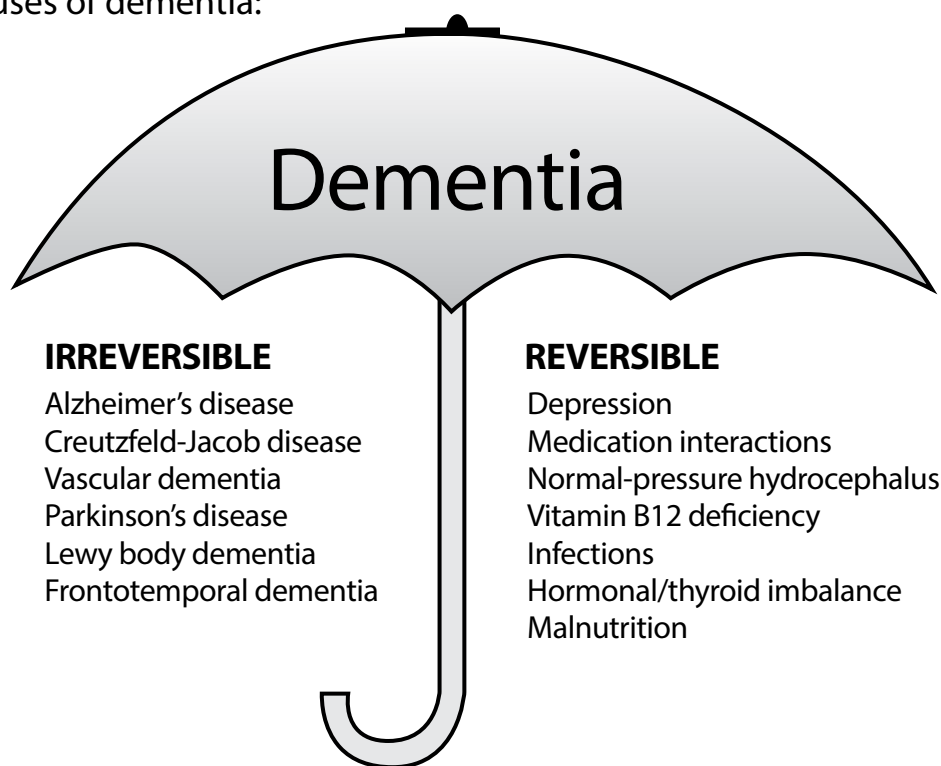
More than 170 diseases cause irreversible dementia, with Alzheimer's disease being the most common. Other common diseases that cause dementia include vascular dementia, Huntington's disease, Creutzfeldt-Jakob disease, Parkinson's disease, and Lewy body disease. Other conditions that can mimic dementia include hydrocephalus, depression, alcoholism, HIV/AIDS, thyroid disorders, drug interactions, and dehydration. Some of these conditions may be treatable or reversible.

Under the umbrella of dementia are examples of the irreversible and reversible causes of dementia:

Understanding Alzheimer's Disease

Alzheimer's disease gradually kills brain cells, destroying a person's memory and ability to learn, reason, communicate, and care for themselves. The disease progresses at different rates. Studies indicate that people aged 65 and older survive an average of four to eight years after a diagnosis of Alzheimer's disease, yet some live as long as 20 years with Alzheimer's.

Alzheimer's disease is not a natural part of aging. Everyone has forgotten where they parked the car or the name of an acquaintance at one time or another. The symptoms of Alzheimer's disease are much more severe than such simple memory lapses. The first symptoms people notice are often forgetfulness and confusion, progressing to memory loss, language problems, and difficulty performing everyday tasks.

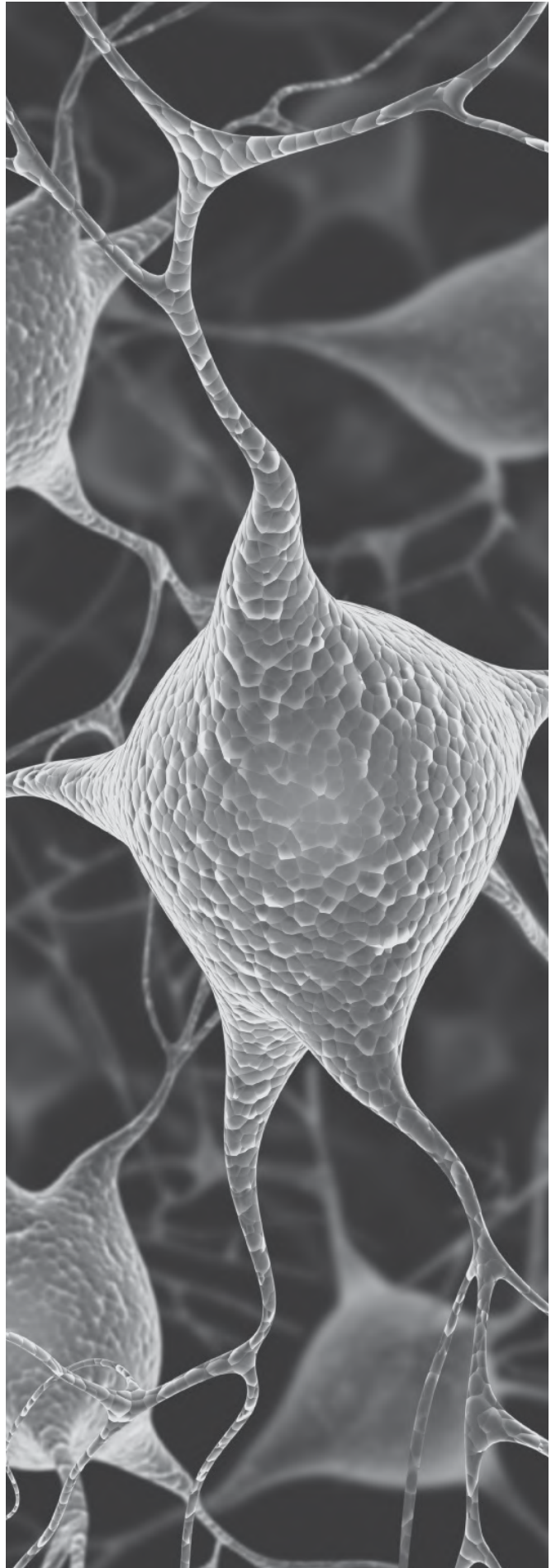


When German physician Alois Alzheimer first described the disease in 1906, it was considered rare. Today, Alzheimer's disease is the most common cause of dementia. More than 5 million Americans have Alzheimer's disease, making it the sixth-leading cause of death.

Alzheimer's disease usually begins gradually, causing a person to forget recent events and to have difficulty performing familiar tasks. Progression of the disease varies from person to person. It can cause confusion, personality and behavior changes, and impaired judgment. Communication becomes difficult as the person with Alzheimer's disease struggles to find words, finish thoughts, or follow directions. Eventually, persons with Alzheimer's disease become totally unable to care for themselves.

What Causes Alzheimer's Disease?

Scientists are still not certain what causes the disease. There is no single known cause of Alzheimer's disease. Age and a family history of Alzheimer's disease are identifiable risk factors for the disease. Scientists are exploring the role of genetics in the development of Alzheimer's disease. Rarer forms of the disease, which strike people in their 30s and 40s, often run within families. Many researchers and physicians are coming to believe that Alzheimer's disease is a complex disease, probably caused by a variety of influences.



What Other Conditions Act Like Alzheimer's Disease?

Creutzfeldt-Jakob disease (CJD) (known as mad cow disease) is a rare, fatal brain disease caused by infection. Symptoms are failing memory, changes in behavior, and lack of muscular coordination. Creutzfeldt-Jakob disease progresses rapidly, usually causing death within a year. No treatment is currently available.

Vascular dementia results from brain damage caused by multiple strokes within the brain. Symptoms can include disorientation, confusion, and behavioral changes. Vascular dementia is neither reversible nor curable, but treatment of underlying conditions (eg, high blood pressure) may halt/slow progression.

Normal pressure hydrocephalus (NPH) is a rare disease caused by a block in the flow of spinal fluid. Symptoms include difficulty in walking, memory loss, and incontinence. Normal pressure hydrocephalus may be related to a history of meningitis, encephalitis, or brain injury and is often correctable with surgery.

Frontotemporal dementia, a rare brain disease, closely resembles Alzheimer's disease, with personality and behavior changes and disorientation that may precede memory loss. As with Alzheimer's disease, diagnosis is difficult.

Parkinson's disease affects control of muscle activity, resulting in tremors, stiffness, and speech impediment. In late stages, dementia can occur. Drugs to treat Parkinson's can improve steadiness and control but have no effect on mental deterioration.

Lewy body dementia is a disease whose the symptoms are a combination of Alzheimer's disease and Parkinson's disease. Usually, dementia symptoms present initially, followed by the abnormal movements associated with Parkinson's. There is no treatment currently available.

Huntington's disease, a hereditary disorder, is characterized by irregular movements of the limbs and facial muscles, a decline in thinking ability, and personality changes. In contrast to Alzheimer's disease, Huntington's can be positively diagnosed and its movement disorders and psychiatric symptoms controlled with drugs. The progressive nature of the disease cannot be stopped.

Depression is a psychiatric condition marked by sadness, inactivity, difficulty with thinking and concentration, feelings of hopelessness, and, in some cases, suicidal tendencies. Many severely depressed persons also display symptoms of memory loss. Depression can often be reversed with treatment.

Medications and Other Medical Conditions Can Mimic Dementia

Common Medications For:

Can Cause Dementia-like Symptoms

High blood pressure,
heart medications

Confusion, memory loss,
depression, fatigue,
disorientation, nervousness,
hallucinations

Depression

Short-term memory
problems, impaired attention
span, confusion, agitation,
delirium, anxiety, insomnia,
sleepiness, disorientation,
irritability

Sleeping problems

Confusion, depression,
disinhibition,
decreased coordination

Arthritis

Depression, psychosis,
paranoia

Diabetes

Acute mental changes

Ulcers

Short term memory loss,
anxiety, disorientation,
depression

Pain

Agitation, hallucinations,
depression

Multiple medications...

Can add to any of the above!

➔ *Ask your pharmacist about possible medication side effects.*

➔ *Call the Alzheimer's Association 24/7 Helpline.*

➔ *Talk to your doctor.*

What Are the Risk Factors for Alzheimer's Disease?

Advancing age – The older one is, the more likely the person will develop Alzheimer's disease.

Family history – One gene has been found to raise the likelihood of developing the disease. This is very rare.

Down syndrome – 25% of those older than 35 years with Down syndrome show signs and symptoms of Alzheimer's disease. The incidence of Alzheimer's in this population is three to five times higher than the general population.

Other health factors – Recent studies have shown persons (specifically women) with diabetes to have a higher prevalence of several other conditions that have been linked to increased risk of cognitive decline, dementia or Alzheimer's, including high blood pressure, high cholesterol, heart disease, obesity, and depression.

10 Warning Signs of Alzheimer's Disease

1. Memory changes that disrupt daily life
2. Challenges in planning or solving problems
3. Difficulty completing familiar tasks
4. Confusion with time and place
5. Trouble understanding visual images and spatial relationships
6. New problems with words in speaking or writing
7. Misplacing things and losing the ability to retrace steps
8. Decreased or poor judgment
9. Withdrawal from work or social activities
10. Changes in mood or personality

Early diagnosis of Alzheimer's disease or other disorders causing dementia is an important step in getting appropriate treatment, care, and support services.



My husband is unable to get out of bed. Late one night he kept calling me, insisting that I call our son and have him take care of the deer that he had just killed. "Okay, I'll do that," I said and left the room. A few minutes later I returned and said, "I called him and he said he will be here in a few minutes, but he asked you to go to sleep until he arrives."

Getting a Diagnosis

When you first notice the warning signs of Alzheimer's or another dementia, we suggest getting a thorough diagnostic workup. Many different things can cause dementia severe enough to interfere with a person's daily routine. Dementia related to depression, drug interaction, and thyroid problems might be reversible if detected early.

An early diagnosis will allow you more time to plan for the future. You can address decisions regarding care, living arrangements, financial and legal matters, and other important issues. It also enables you to establish a family medical history with Alzheimer's disease.

Alzheimer's disease can strike persons in their 30s, 40s, and 50s. This younger-onset form of Alzheimer's disease presents unique planning issues for families.

New technology is emerging in the field of Alzheimer's disease diagnostics, but it remains a multistep process that includes a psychosocial, physical, and neurological examination and a psychiatric assessment. Laboratory tests are also evaluated. You can expect the following to happen during the multistep process:

1. Determination of medical history

The caregiver, the individual being tested, and other family members will be interviewed both individually and together to gather background information on daily functioning, current mental and physical condition, and family medical history. Contact the Alzheimer's Association 24/7 Helpline at 800-272-3900 for suggestions on how to prepare for the initial appointment.

2. Mental status evaluation

The mental status evaluation assesses sense of time and place and the ability to remember, understand, talk, and do simple calculations. The clinician may ask, "What year is it? What day of the week is it? Who is the current president? The evaluation will also involve mental exercises, such as spelling a word backward, writing a sentence, or copying a design. When reviewing the test results, the physician will consider overall performance in relation to educational background, occupation, and age.

3. Physical examination

A physician will evaluate nutritional status and check blood pressure and pulse. The physician will also search for the presence of cardiac, respiratory, liver, kidney, and thyroid diseases, and atherosclerosis (hardening of the arteries). Some of these conditions can cause dementia-like symptoms.

4. Neurological exam

A physician—usually a neurologist—will closely evaluate the individual's nervous system for problems that may signal brain disorders other than Alzheimer's disease. The physician will search for evidence of previous strokes, Parkinson's disease, hydrocephalus (fluid accumulation in the brain), a brain tumor, or other illnesses that impair memory and/or thinking. The physician will test coordination, muscle tone, strength, eye movement, speech, and sensation.

5. Laboratory tests

A variety of laboratory tests will be ordered by the physician to help diagnose Alzheimer's disease by ruling out other disorders. A complete blood count and blood chemistry will be ordered to detect anemia, infection, diabetes, and kidney and liver disorders. Levels of vitamin B12 and folic acid (a vitamin produced by the body) are measured, as low levels can be associated with dementia. Because very high or low amounts of the thyroid hormone can cause confusion or dementia, thyroid levels are measured through a blood test.

The physician may also order an electrocardiogram (EEG) to detect abnormal brain wave activity. This test can detect conditions such as epilepsy, which can sometimes cause prolonged mild seizures that leave a person in a confused state.

A computerized tomography (CT) scan, which takes X-ray images of the brain, is also frequently used. The brain is scanned for evidence of tumors, strokes, blood clots, and hydrocephalus. Magnetic resonance imaging (MRI) is another brain-imaging technique sometimes used. More experimental tests may also be recommended but are not necessary for the diagnosis. These include: positron emission tomography (PET) scans, which show how different areas of the brain respond when the person is asked to perform different activities, such as reading, listening to music, or talking; and single proton emission tomography (SPECT) scans, which show how blood is circulating to the brain.

6. Psychiatric, psychological, and other evaluations

A psychiatric evaluation can rule out the presence of other illnesses, such as depression, that result in memory loss similar to dementia of the Alzheimer type. Neuropsychological testing may also be done to test memory, reasoning, writing, vision-motor coordination, and the ability to express ideas. These tests may take several hours and involve interviews with a psychologist as well as written tests. These tests provide more in-depth information than the mental status evaluation.

Nurses and occupational, rehabilitation, physical, or speech therapists may be called upon to look for problems with memory, reasoning, language, and judgment affecting daily functioning.

Understanding the Diagnosis

Once testing is completed, the diagnosing physician or other members of the diagnostic team will review the results of the examinations, laboratory tests, and other consultations to arrive at a diagnosis. If all test results appear to be consistent with Alzheimer's disease, the clinical diagnosis will be "probable Alzheimer's disease," or "dementia of the Alzheimer type." If the symptoms are not typical, but no other cause is found, the diagnosis will be "possible Alzheimer's disease."

Although researchers have made enormous progress in diagnostic testing, the only way to prove Alzheimer's disease is through an autopsy. However, if a thorough workup is completed, the diagnosis is quite accurate.

Treatment of Alzheimer's Disease

Until recently, nothing seemed to slow the cognitive decline caused by Alzheimer's disease. However, as researchers have learned more about the development of the disease, several promising treatments have been identified. Five prescription drugs are approved by the U.S. Food and Drug Administration (FDA) to treat people who have been diagnosed with Alzheimer's disease. Treating the symptoms of Alzheimer's disease can provide people with comfort, dignity, and independence for a longer period of time and can encourage and assist their caregivers as well. These medications do not stop the disease itself but may slow the progression for a limited time.



Medications for Mild to Moderate Alzheimer's Disease

Four medications, called cholinesterase inhibitors, are prescribed for the treatment of mild to moderate Alzheimer's disease. They may help delay or prevent symptoms from becoming worse for a limited time and may help control some behavioral symptoms. The medications are: galantamine (Razadyne), rivastigmine (Exelon), donepezil (Aricept), and tacrine (Cognex). Scientists do not yet fully understand how cholinesterase inhibitors work to treat Alzheimer's disease, but current research indicates that they prevent the breakdown of acetylcholine, a brain chemical believed to be important for memory and thinking. As Alzheimer's disease progresses, the brain produces less and less acetylcholine; therefore, cholinesterase inhibitors may eventually lose their effect.

No published study directly compares these medicines. Because all four work in a similar way, it is not expected that switching from one of these drugs to another will produce significantly different results. However, a person with Alzheimer's disease may respond better to one drug than another. Cognex is no longer actively marketed by the manufacturer.

Medication for Moderate to Severe Alzheimer's Disease

The fifth approved medication, known as memantine (Namenda), is an N-methyl D-aspartate (NMDA) antagonist. Approved by the FDA in 2003, it is the only medication approved to treat moderate to severe Alzheimer's disease. Studies have shown that the main effect of memantine is to delay progression of some of the symptoms of moderate to severe Alzheimer's disease. The drug may allow patients to maintain certain daily functions a little longer. For example, Namenda may help a person in the later stages of Alzheimer's disease maintain the ability to go to the bathroom independently for several more months, a benefit for both patients and caregivers.

Namenda is believed to work by regulating glutamate, a brain chemical that, when produced in excessive amounts, may lead to brain cell death. Because NMDA antagonists work very differently from cholinesterase inhibitors, the two types of drugs are often prescribed in combination.



The Seven Stages of Alzheimer's Disease

Alzheimer's disease is progressive. Experts have developed "stages" to describe how a person's abilities change from "normal function" through "advanced Alzheimer's." The stages are general guides, and symptoms vary greatly. Every person is unique, but we can speak about some common patterns of the illness. Those with Alzheimer's live an average of four to eight years after their symptoms become noticeable to other people but can live as long as 20 years, depending on age and other health conditions.

Stage 1: No Impairment

Person has normal function.

The individual does not experience any memory problems. An interview with a medical professional does not show any evidence of symptoms.

Stage 2: Very Mild Decline

Changes may be normal, age-related changes or earliest signs of Alzheimer's.

The individual may feel that he or she is having memory lapses, forgetting familiar words or the location of everyday objects. Still, symptoms cannot be detected by others.

Stage 3: Mild Cognitive Decline

Early-stage Alzheimer's may be diagnosed in some but not all individuals at this point.

Friends, family, or co-workers begin to notice difficulties. During a detailed medical interview, doctors may be able to detect problems in memory or concentration.

Common stage 3 difficulties include:

- Noticeable problems coming up with the right word or name
- Trouble remembering names when introduced to new people
- Having noticeably greater difficulty performing tasks in social or work settings
- Forgetting material just read
- Losing or misplacing a valuable object
- Increasing trouble with planning or organizing

How you can help during this time

- Pay close attention to the frustration and anger – remind yourself that it is a sign of confusion and fear.
- Offer support and help in a calm, non-critical manner.
- Carefully organize and simplify daily routine.
- Encourage activities that allow for independence and success.
- Begin to consider driving alternatives.
- Allow for meaningful contributions to family chores.

Stage 4: Moderate Cognitive Decline

Mild or early-stage Alzheimer's is diagnosed.

At this point, a careful medical interview should be able to detect clear-cut problems in several areas:

- Forgetfulness of recent events
- Impaired ability to perform challenging mental arithmetic; for example, counting backward from 100 by sevens
- Greater difficulty performing complex tasks, such as planning dinner for guests, paying bills, or managing finances
- Forgetfulness about one's own personal history
- Becoming moody or withdrawn, especially in socially or mentally challenging situations



How you can help during this time

- Celebrate success (but don't overdo it) – "You ate all your ice cream, Mom. Very good." "You did a good job brushing your teeth, John."
- Accept that he/she will not talk to you at times.

Stage 5: Moderately Severe Cognitive Decline

Gaps in memory and thinking are noticeable, and individuals begin to need help with day-to-day activities.

At this stage, those with Alzheimer's may:

- Be unable to recall their own address or phone number or the high school or college from which they graduated
- Become confused about where they are or what day it is
- Have trouble with less challenging mental arithmetic, such as counting backward from 40 by subtracting fours, or from 20 by twos
- Need help choosing proper clothing for the season or occasion
- Still remember significant details about themselves and their family
- Still require no assistance eating or using the toilet

How you can help during this time

- Be calm and patient – remind yourself that poor judgment, behavior problems and restlessness are signs of confusion and fear.
- Give simple, one-step directions. ("Put this towel in your hand. Now dry your hands with the towel.") Do not use words like "and", "but", "or", "maybe" or "which one?"
- Limit choices – do the same things the same way each time, do them one step at a time.
- Gently remind and repeat.
- Speak in a normal voice; a person with Alzheimer's is not necessarily hearing impaired.
- Do not argue or expect them to think rationally.
- Reduce noise and activity that may confuse, frighten or agitate – run the dishwasher and garbage disposal, vacuum the floors, etc., when he/she is asleep, out of earshot, or away from the house.

Stage 6: Severe Cognitive Decline

Memory continues to worsen, personality changes may take place, and individuals need significant help with daily activities.

The person may:

- Lose awareness of recent experiences as well as their surroundings
- Remember their own name but have difficulty with their personal history
- Distinguish family and unfamiliar faces but have trouble remembering the name of a spouse or caregiver
- Need help dressing properly and may, without supervision, make mistakes, such as putting pajamas over daytime clothes or shoes on the wrong feet
- Experience major changes in sleep patterns: sleeping during the day and becoming restless at night

- Need help handling details of the toilet (for example: flushing the toilet, wiping or disposing of tissue properly)
- Have increasingly frequent trouble controlling their bladder or bowels
- Experience major personality and behavioral changes, including suspiciousness and delusions (such as believing the caregiver is an imposter) or compulsive, repetitive behaviors like hand-wringing or tissue shredding
- Tend to wander or become lost



Stage 7: Very Severe Cognitive Decline

Severe or late-stage Alzheimer's is evident.

In the final stage of this disease, individuals lose the ability to respond to the environment, to carry on a conversation, and eventually, to control movement. They may still say words or phrases.

At this stage, individuals need help with much of their daily personal care, including eating and using the toilet. They may also lose the ability to smile, to sit without support, and to hold their head up. Reflexes become abnormal. Muscles grow rigid. Swallowing is impaired.

Coping With Feelings

You may want to seek emotional support, particularly during this last, difficult stage of the disease. Local chapters of the Alzheimer's Association have support groups and a 24/7 Helpline that can help you work through the emotions you may be experiencing, including stress, grief, guilt, anger, and depression. Call 800-272-3900.

How you can help during this time

- 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.
- 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.
- 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.
- The Alzheimer's Association advocates palliative (comfort) care for individuals with late-stage disease, believing that efforts at life extension create burdens and avoidable suffering.

Younger-Onset Alzheimer's Disease

Younger-onset Alzheimer's is the name for the disease when it affects people under the age of 65. It can occur in people in their 30s, 40s, and 50s. Younger-onset accounts for up to 10 percent of Alzheimer's cases. The seven stages described previously also apply to younger-onset Alzheimer's disease. Although it tends to progress faster in younger people, Alzheimer's disease affects each person individually.

The diagnosis of younger-onset Alzheimer's can be shocking to families and the professionals involved. If your loved one has younger-onset Alzheimer's, you may experience feelings of denial, isolation, frustration, loss, anger, fear, depression, and sadness. You may express emotions and cope with frustrations by:

- Joining an Alzheimer's Association support group for younger-onset Alzheimer's disease
- Sharing feelings with a professional counselor, family, friends, or clergy.
- Seeking out as much information as possible and confirming your findings with a healthcare provider

Individuals with younger-onset Alzheimer's disease live meaningful and productive lives by engaging in activities and interests they still enjoy and finding comfort in family and

friends. Caring for someone with younger-onset Alzheimer's can mean dealing with some life transitions sooner than anticipated.

Individuals with younger-onset Alzheimer's disease can:

- Continue to work as long as they or their physician feel they're able
- Use reminders, memos, and a calendar to help perform tasks
- Participate in legal and financial planning
- Educate themselves, as well as their spouse or guardian, about the Social Security benefits available to them through Compassionate Care Allowance and how those benefits can be claimed
- Seek professional counseling to discuss role reversals, intimacy, and sexuality issues
- Research early retirement options
- Talk openly with children about the changes being experienced as a result of the disease
- Give children an opportunity to express their feelings and concerns
- Share their experience of living with Alzheimer's disease with friends, coworkers, and neighbors and let them know when help is needed
- Continue social activities as much as possible

It is important to know that:

- The disease affects each person differently and symptoms will vary.
- You will have good days and bad days.
- Genetic research has found connections between a number of genes and Alzheimer's disease in a small percentage of families with Alzheimer's. Currently, there are at least three genes that have been associated with early-onset familial Alzheimer's.
- You are not alone – there are people who understand what you are going through and can help you and your family.

SECTION 2:

RECOMMENDED ACTION STEPS

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Step 1: Tell Family and Friends

Everyone in the Family Is Impacted

Alzheimer's causes significant changes in family life. Spouses, partners, adult children, and school-age children become caregivers. Caregiving can make recreation, chores, and even employment difficult or impossible to maintain. Alzheimer's will impact a family's social, financial, physical, emotional, and spiritual lives. This disease will present challenges that many families have never experienced.

It Helps When Everyone Understands the Disease

All family members who have contact with the person with Alzheimer's disease can learn how to communicate effectively with their loved one. This can be challenging. He or she may not understand how to communicate in a manner that is consistent with what has become "normal and appropriate" for the diagnosed person.

For this reason, it can be particularly valuable for all family members to:

- Call the Alzheimer's Association 24/7 Helpline for one-on-one disease education
- Read books on the subject and study the educational brochures available at the Alzheimer's Association
- Attend an Alzheimer's Association support group
- Attend Alzheimer's Association caregiver education programs

- Participate in the Alzheimer's Association Walk to End Alzheimer's® or The Longest Day®

We suggest that all family members talk with the primary caregiver to learn about the current care conditions. Friends, relatives, and anyone who interacts with the diagnosed person and the direct caregivers can benefit from understanding what daily life is like for them.

Individuals React Differently

Family relationships that are complicated can become more so when caring for a loved one with Alzheimer's disease. Challenges and issues within families are normal and common. Alzheimer's disease can increase the stress and strain on family relationships but may also bring family and friends closer to each other.

Your reaction could be very different from your friends' or family members' reactions. Some people require more time than others to adjust to the shocking news that a loved one has been diagnosed with Alzheimer's disease.

While Alzheimer's disease may bring family members together, others may retreat or need time to process the information. Disease, disability, and the dying process will challenge each person in profound ways.

Family Expectations/Dynamics

Each member of the family has the opportunity to respond to the challenges in his or her own particular way. For some families, there is an overall theme of support and earnest collaboration. Each person who has the desire to help can find a task that is appropriate. For example:

- A relative may have organizational skills to schedule caregivers, develop job descriptions, create forms for tracking care activities, and make the house "Alzheimer's safe."
- Someone that is skilled in finances could create a projection of costs, pay bills, and balance accounts.
- Another person might dedicate time each week to do the grocery shopping, clean the house, and provide respite for the primary caregiver.
- A long-distance caregiver can visit for a weekend to provide respite or assist with financial planning.

Keep Everyone Informed

When you share the diagnosis of Alzheimer's disease in a loved one, you may receive help in ways you never anticipated from family, friends, and neighbors. Being able to help makes people feel good. Others may be going through a similar process and will want to share experiences. Use the Care Calendar at www.alz.org® to keep everyone informed and organized through the caregiving journey.

To make the information available to your support system, you can also:

- Write a periodic e-mail
- Arrange for a family member to write the note and/or make periodic phone calls
- Invite family members and friends to attend a support group, an education program, or an event in their area (Walk to End Alzheimer's, The Longest Day)
- Request multiple copies of brochures from the Alzheimer's Association to give to family and friends



Resolving Family Conflicts

Family members benefit from ongoing discussion when making decisions on behalf of their loved ones. Some members may disagree about a recommended treatment and get angry or defensive. Or, they may refuse to engage in discussion because they feel the family is planning for death rather than care. Here are some suggestions:

Involve a third party. A social worker, pastor, or Alzheimer's Association care consultant can be called on to facilitate family meetings and help members work through difficult issues.

Listen to each family member with respect. Family members may have different opinions of the person's quality of life or healthcare preferences. Or, they may be at different levels of acceptance about their loved one's diagnosis. Talking about these perspectives may bring intense emotions to the surface. Work to create an atmosphere of respect where family members are not blamed or attacked.

Come to an agreement. Talk to the care consultant about the person's condition, prognosis, and care options, including the burdens and benefits of specific treatments. With the help of a third party, a family can find common ground and agree on decisions that are in the best interest of the person with the disease.

Helping Children and Teens Cope

When children or teens learn that a parent, grandparent, relative, friend, or neighbor is diagnosed with Alzheimer's disease, they may experience a range of feelings. The degree to which children and teens are affected by the disease depends on who has it (parent, grandparent, relative, or friend), how close they are to the person, and where that person lives. The impact is usually greatest when a parent has the disease and when the person lives in the same home.

Feelings children/teens may experience:

- Sadness about changes in person's personality and behavior
- Confusion about how people develop the disease and why the person behaves differently
- Fear of the person's behavior changes
- Fear that they or their parents might develop the disease
- Anger or frustration caused by the need to repeat activities or questions
- Anger about how the disease affects the family
- Guilt for getting angry or being short-tempered with the person
- Loneliness, jealousy, or resentment because of the increased amount of time and attention given to the person
- Embarrassment about having friends or other visitors see the person behaving differently

Tips when talking with children/teens about Alzheimer's:

- Take time to educate them about the disease and encourage them to ask questions.
- Help them talk about their emotions and feelings.
- Let them know these feelings are normal.
- Offer comfort and support.
- Respond honestly to questions.
- Maintain communication and continue to provide opportunities for them to express their feelings.
- Show empathy regarding the loss that they are experiencing at a crucial stage of their lives.

You may encounter:

- Various emotions of sadness, confusion, fear, anger, frustration, guilt, jealousy, resentfulness, and embarrassment are normal.
- Some obvious signs that indicate the need for immediate and effective intervention include destructive behaviors like crime, truancy, drug use, or violence against other persons and animals.
- Poor judgment on the part of the person with Alzheimer's may cause irrational behavior from which the child or teen needs competent adult intervention. The diagnosed person may not be in a position to supervise

children. A child or teen may need to be protected from the diagnosed person.

Outside parties can be helpful:

- Talk to the adolescent, other family members, teachers, or friends about what is happening, possible reasons, and potential solutions.
- Children/teens need someone to talk to who is nonjudgmental, who can listen and assist.
- You may get a referral to a qualified therapist who understands Alzheimer's disease and the effects of the illness on young people. Contact the local Alzheimer's Association chapter for suggestions.



Step 2: Planning Care

Alzheimer's disease can be a prolonged illness, and ongoing caregiver education and support is available to you. Talking about concerns can help you meet the challenges of caregiving today while planning for changes tomorrow. The following recommendations are designed to help you focus your loved one's plan of care. More personalized care planning, education, and support is available through the Alzheimer's Association. You will work with a licensed social worker in person or by telephone to develop a plan of care to assist you and your family. Contact the Helpline at 800-272-3900.

Listen to those who care. If they are telling you that you need help, listen to their concerns.

Identify strengths. Identify abilities or special qualities that will help in difficult situations.

Choose one issue. From the list of health and safety measures, personal care, social needs, or respite, choose one that will leverage other benefits. Many caregivers are paralyzed by the magnitude of their tasks.

Experiment. Various care options might work. Experiment until a good fit is found. Taking action is key!

Take small steps, one at a time. It is easier for someone with dementia to agree to a short visit to a day care center and then return another day than to commit to a whole program at once.

Call in the allies. Ask for help from someone with whom your loved one is cooperative. Consider a family meeting to decide strategies and roles.

Remember: Care decisions involve choices among imperfect options.



Step 3: Seek Professional Legal and Financial Advice

You may be worried about the cost of future care and if you will have enough money to cover these costs. Discussing your immediate and future financial needs and goals will help protect you and the people who depend on you financially. Work with a financial advisor and trusted family member or friend to determine the following:

- Potential care expenses, such as follow-up physician visits, prescription medications, care services, and housing
- Current sources of income, such as insurance, personal savings, investments, Social Security, and employee or retirement benefits
- Other financial resources available through government assistance or community-based organizations

Healthcare Insurance

Healthcare insurance may include private and retiree insurance and Medicare. For more detailed information, contact the Medicare office at 1-800-MEDICARE (1-800-633-4227) or visit medicare.gov.

Medicare – Medicare is a federal health insurance program for people 65 years and older, people under age 65 with certain disabilities, and for people of all ages with end-stage renal disease (permanent kidney failure requiring dialysis or a kidney transplant). Medicare Part A covers inpatient hospital care, and Medicare Part B covers a portion of the doctor's fees and other medical expenses.

Medicare Part D is prescription drug coverage. Choosing the right Medicare Part D plan is important, and there are many options. Medicare covers skilled needs either at home or in a nursing home but does not cover custodial care in either location. Visit www.medicare.gov, call 1-800-MEDICARE, or contact the Senior Health Insurance Information Program (SHIIP) at 1-800-452-4800 for assistance in picking the right plan for you. (SHIIP is a free counseling service offered by the Indiana State Department of Insurance.) Open enrollment for Medicare is usually October through December.

Medigap – Medicare coverage can be supplemented with Medigap, a private insurance that covers copayments and deductibles required by Medicare. Visit www.medicare.gov or call SHIIP for more information on Medigap.

Medicaid – Because Medicaid is a federal program administered by each state's social services agency, eligibility and benefits vary from state to state. Medicaid covers all or a portion of nursing home costs. A person with Alzheimer's disease can qualify for Medicaid assistance in long-term care only if he or she has minimal income and cash assets. It is advisable to consult an elder-law attorney in order to complete financial planning for Medicaid eligibility.

Personal Resources

Retirement benefits that provide critical financial resources include retirement plans, individual retirement accounts (IRAs), annuities, and Social Security. Investment assets (stocks and bonds, savings accounts, real estate, etc) and personal property (jewelry and artwork) can be sources of income. Money from the sale of a home can be invested.

Social Security Disability

This is a program to assist wage earners younger than age 65 who can no longer work because they are disabled. To apply, you must have worked a minimum of five consecutive years in the past 10 years and establish disability status. You do this by submitting physician statements and other documentation to your local Social Security office or you can apply online. For more information, visit the Social Security Administration's Web site at ssa.gov. Younger-onset Alzheimer's disease is now on the Social Security Administration's compassionate allowances list, which means that eligibility is expedited.



Supplementary Security Income

This program guarantees a minimum monthly income to persons who are age 65 or older, disabled, or blind and have limited income and assets. It is important to apply soon after a diagnosis is made because payments ordinarily begin with the date of application or eligibility.

Veterans Benefits

There are many services available for eligible veterans. If you are receiving care at a Veterans Administration (VA) hospital or clinic, ask your nurse or social worker about possible respite options. The VA Aide and Attendance program is a cash benefit available to help pay for care. This program has both dates of service and financial eligibility requirements. The VA website is VA.gov.

Long-term Care Insurance

Long-term care insurance is private insurance that pays for home care, assisted living, or nursing home care. Each policy is different and has many options. Some policies require that one of their nurses make an in-home assessment of the insured. Most have a 90-day waiver where the insured has to pay for care out of pocket for 90 days before the policy will begin payments. Check with the insurer about benefits and payments before making any care arrangements.

Determining Legal Capacity

Legal planning should begin soon after a diagnosis is made and includes putting in place documents that:

- Authorize another person to make healthcare and financial decisions
- Include financial plans for long-term care coverage

- Set out advance directives

If the person with Alzheimer's disease has legal capacity—the level of mental functioning necessary to sign official documents—he or she should actively participate in the legal planning process.

Generally speaking, if an individual with Alzheimer's disease has sufficient cognitive ability to understand the meaning and significance of a legal document, he or she probably has the legal capacity to execute it. An attorney can help determine the level of legal capacity required to execute a particular document since the level of legal capacity required may vary from one document to another.

It is important to determine whether or not the person with Alzheimer's disease is able to understand explanations of legal documents and the implications of signing them. In order to do this:

- Talk to the person with Alzheimer's disease to find out if they understand what is being explained or asked.
- Consult a medical professional if there is a question as to whether or not the person with Alzheimer's disease has legal capacity.
- Take inventory of existing legal documents.
- Check to see if living wills, trusts, and powers of attorney were executed prior to the diagnosis of Alzheimer's disease.

Understanding Legal Documents

Commonly used documents in legal planning for individuals with Alzheimer's disease include:

Power of attorney – A power of attorney document gives a person with Alzheimer's disease (the principal) an opportunity to authorize an agent (usually a trusted family member or friend) to legally make decisions when they are no longer able to do so. Most powers of attorney are "durable," meaning that they are valid even after the principal is no longer competent.

A power of attorney can be changed or withdrawn at any time and does not give the agent authority to override the decision making of the principal. So, in essence, as long as the person with Alzheimer's disease is competent, he or she maintains the right to make his or her own decisions, even if the decisions are not what others believe are good decisions.

The agent, under a power of attorney for property, is authorized to manage and make decisions regarding the income and assets of the principal. This person is responsible for acting according to the instructions and in the best interests of the person with Alzheimer's disease.

Power of attorney for healthcare –

The power of attorney for healthcare document appoints an agent to make all decisions regarding healthcare, including choices regarding healthcare providers, medical treatment, and facilities. For persons in the later stages of Alzheimer's disease, the healthcare agent will (in the absence of advance directives) choose care services, make end-of-life decisions, such as whether or not the person with Alzheimer's disease is given artificial nutrition, or issue "do not resuscitate" directives. Different states have different rules about which the healthcare decision maker can be if the document does not exist.

Living will – In a living will, the person with Alzheimer's disease expresses his/her decision on the use of artificial life support systems. It is useful only in situations where a physician has determined that the person is irreversibly ill or critically injured and near death.

Out-of-hospital do not resuscitate (DNR)

This document is signed by both the person with Alzheimer's (or the health-care power of attorney) and the doctor to ensure that emergency personnel will not attempt resuscitation when a person is at home and in a crisis. Emergency personnel will provide comfort care and, possibly, transportation to the hospital, but they will not perform life-saving procedures. This document would be created in addition to a living will and/or power of attorney for healthcare.

Will – A will is a document created by an individual that names an executor (the person who will manage the estate) and the beneficiaries (the person or persons who will receive the estate) at the time of death. Wills are effective only when the individual who created and executed the will dies. An executor named in a will has no authority to act during the lifetime of the individual making the will. A will cannot be used to communicate healthcare preferences; however, it can give an individual peace of mind that his or her wishes will be fulfilled after death. Everyone, including those with Alzheimer's disease, benefit from having a will.

Physician Orders for Scope of Treatment (POST)

– This form is available in Indiana at indianapost.org. It is an advance care planning tool that helps ensure treatment preferences are honored. It is designed for people with serious illness. Preferences for life-sustaining treatments including resuscitation, medical interventions, antibiotics, and artificial nutrition are documented as medical orders. It must be reviewed and signed by a physician to be activated. This form transfers throughout the health care system, and the orders are valid in all care settings.

Guardianship/conservatorship

– A caregiver of an individual who no longer has legal capacity to execute powers of attorney or trusts may have to become that individual's guardian or conservator.

Guardianship is a legal proceeding where, based upon medical evidence, a court finds that a person is legally incompetent—in the case of Alzheimer's disease, because of cognitive impairment—and unable to make decisions relating to his/her care and the management of assets. Once an individual is found to be legally incompetent, the court appoints a guardian or conservator. A guardian has the legal authority to make decisions regarding the care and custody of the person with Alzheimer's disease.

After filing a petition for guardianship, a summons—a notice to appear in court—and a copy of the petition are delivered to the individual with Alzheimer's

disease. The petition includes the name of the person seeking to act as guardian. The person with Alzheimer's disease has an opportunity to object to the guardianship; if there are no objections, a guardian is appointed. A hearing may be held by the court when an objection to the petition for guardianship is raised by the person with Alzheimer's disease or other individuals.

Finding a Lawyer

We suggest obtaining legal advice and services from an attorney who practices in the area of elder law. Elder law is a specialized area of law focusing on guardianship, disability planning, long-term care/Medicaid planning, and other related legal areas that typically affect older adults. Legal advice and services may be provided by a referral from a family attorney. For a listing of elder-law attorneys in Indiana, call the Alzheimer's Association 24/7 Helpline at 1-800-272-3900.

Free legal advice may be available in your community. Legal Services Providers, which is funded by the Older Americans Act and coordinated by Area Agencies on Aging, provides free legal assistance to adults age 60 and older. Areas covered are the same counties as Area Agencies on Aging. There are no income or assets eligibility requirements; however, the type of services available varies from area to area. Call the Alzheimer's Association 24/7 Helpline and request the listing of legal services providers for older adults in Indiana.

Preparing for Your Legal Appointment

All documents relating to the assets of the individual with Alzheimer's disease should be gathered ahead of time and shared with your lawyer. These documents may include:

- An itemized list of assets, with current value, including whose names are on the accounts or ownership documents
- Copies of all estate-planning documents, including wills, trusts, and powers of attorney
- Copies of all deeds to real estate
- Copies of recent income tax returns
- Life insurance policies and cash values of policies
- Health insurance policies or benefit booklets
- Admission agreements to any healthcare facilities
- A list of names, addresses, and phone numbers of involved family members, financial planners, accountants, and the physician of record

Talking With Your Attorney

Be sure to discuss options for healthcare decision making and property management for the person with Alzheimer's disease. Also inquire about possible coverage of long-term care services, including what is provided by Medicare, Medicaid, and other health insurance.

Tips for Legal Planning

- Always name a successor or "back up" agent in the event that the primary agent becomes unable or unwilling to act.
- Consider a neutral third person as an agent under the power of attorney if immediate family members don't get along.
- If there is no family member available who has the time or expertise to manage the estate of the person with Alzheimer's disease, consider having a bank manage the estate.
- Be sure that all designated individuals have a copy of the power of attorney document and have access to the original document.
- Be sure that physicians and other healthcare providers have a copy of the power of attorney for healthcare and a signed living will on file.
- Avoid out-of-state agents or multiple agents if possible.
- Remember, being a spouse does not guarantee enough legal authority to make decisions for someone.

For more information:

Call the Alzheimer's Association 24/7 Helpline at 800-272-3900 for brochures on legal and financial planning. We also have local legal resources available in our Resource Guides. We offer a legal and financial planning program either in person or online at alz.org. For local offerings, visit our website at alz.org/indiana or call the Helpline.



Step 4: MedicAlert® + Alzheimer's Association Safe Return®

The Alzheimer's Association and MedicAlert® have formed an alliance to improve the safety of individuals with Alzheimer's or other dementia. MedicAlert® + Alzheimer's Association Safe Return® is a 24-hour nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or who have a medical emergency.

How MedicAlert® + Safe Return® Works

If an individual with Alzheimer's disease wanders and becomes lost, first call 911. Then caregivers should call the 24-hour emergency response line (1-800-625-3780) to report the incident. A community support network will be activated, including local Alzheimer's Association chapters and law enforcement agencies, to help reunite the family member or caregiver with the person who wandered. With this enhanced service, critical medical information will be provided to emergency responders when needed.

MedicAlert® + Safe Return® Features

- One identification product (bracelet or necklace) that serves two purposes: It provides emergency medical information and assists in the event of a wandering incident.
- The member's personal health record lists medical conditions, medications, and allergies and can be updated 24 hours a day through a private online account or by calling the toll-free number during business hours.

- A national database includes a member's photo and emergency contact information to help reunite the lost person with his or her caregivers.
- The database will also keep copies of living wills and healthcare power of attorney documents on file.
- There is also a program for the caregiver that keeps all of the same information on file.

Cost for MedicAlert® + Safe Return® Products

The enrollment fee is \$55, with an annual renewal fee of \$35. The enrollment kit includes: 24-hour emergency response system, ID jewelry (bracelet or necklace), personalized emergency wallet card, personal health record, and "6 Steps to a Safe Return" refrigerator magnet, which provides useful tips when someone is missing. (All prices are subject to change.)

Companion caregiver jewelry can be purchased for \$35, with an annual renewal fee of \$35, which includes everything listed above.

For safety and peace of mind, enroll in MedicAlert® + Safe Return® today: call 1-888-572-8566 or online at medicalert.org/safereturn.

For other safety tips and wandering prevention ideas, call the Alzheimer's Association 24/7 Helpline at 800-272-3900.

Step 5: Plan Ahead for Respite Care

Taking a break from caregiving responsibilities is often referred to as “respite.” The more rested you are, the better care you can give your loved one and the better you will be able to cope. Caregivers often suffer extreme physical and emotional distress from the heavy burden of providing 24-hour care. By taking a break, you will have better health and may be able to keep your loved one at home longer. Three types of respite care are commonly available:

Adult day care – Adult day care centers are designed to offer stimulating activities, socialization, and care for those who should not be left alone during the day. A hot meal is usually provided, and transportation may be available.

In-home care – Visiting nurses, home health aides, companions, homemakers, and volunteers can provide services at home such as bathing, dressing, or supervision.

Residential respite – Some nursing homes and other residential facilities offer short-term stays of a few days or a few weeks. This is a good option if permanent placement will eventually be needed as it allows the person to get used to the atmosphere.

There are some barriers to the use of respite care. The inability to “let go” can be overwhelming. You may feel no one can do as good a job or know the routines and needs of the person with Alzheimer’s as well as you. You may need to make a conscious effort to overcome some of the barriers to getting help with caregiving.

Also look for:

Feelings of guilt – You may have feelings of guilt and see respite as shirking your responsibilities. You may see asking for help as a personal failure. Guilt can also occur over the relief and enjoyment of free time after respite services have been started.

Financial costs of respite services – You may fear the high costs of long-term care or in-home services. Consider that the use of respite services is cost-effective if it saves your health and prolongs home care of your loved one. Respite care is a tool to sustain the family’s ability to provide care. There may be assistance available from your Area Agency on Aging. Some providers have financial assistance, so always ask.

Seeking help too late – Many begin to seek respite care too late for the person with Alzheimer’s disease or the caregiver to benefit from services. It is important to start respite services early in the caregiving process. Respite is to prevent caregiver burnout, not treat it.

For more information

Call the Alzheimer’s Association Helpline at 800-272-3900 for lists of available agencies in your area. We also have tip sheets and suggestions to help caregivers find the best agency for you and your loved one.

Step 6: Anticipate Caregiving Needs for the Late Stage

Making decisions on behalf of the person you care for may be a pivotal part of your responsibilities. With the passage of time, these decisions may grow in difficulty and significance. Among the most profound is assuring that the person's most basic needs for respect, dignity, and physical comfort are sustained until the end of life.

By doing all you can now to learn what changes Alzheimer's disease will likely bring, you'll be better prepared to make some of the more difficult decisions that may accompany the later stages of the disease. Working out such issues before a crisis arises will allow you the best opportunity to anticipate the needs of the person you care for and to make informed decisions that are consistent with his or her desires.

Equally important, thinking ahead will make it possible for you to invest your energies in making the time with the person with Alzheimer's disease as meaningful and as memorable as possible.

Medical Risks

Because of the physical and mental decline that results from Alzheimer's disease, the person you care for becomes more vulnerable to other problems, some of which can be life threatening. Dehydration resulting from an inability to eat and drink is one serious risk. Be watchful of the following physical care needs:

Skin care – Keeping skin dry and clean is important. Check daily for rashes, sores, and any skin breakdowns. Moisturize dry areas of skin or any place with skin-to-skin contact. Minimize pressure to bony prominences such as the elbows, knees, and ankles.

Infections – Urinary tract infections and pneumonia are the most common types of infection in people with Alzheimer's. Any sudden memory or behavioral change may be a sign of infection, so call the doctor. Talk with the healthcare provider of the person with Alzheimer's whenever you have a concern about infection.

Traumas – Fractures as the result of falls or other trauma can lead to complications and be a possible cause of death for people with Alzheimer's disease. Keeping their surroundings as safe as possible can help minimize this risk.

Difficulty swallowing – As the person with Alzheimer's disease declines, problems with swallowing may develop. This problem can make the person at risk for aspiration pneumonia. You may have to change food consistency. A speech therapist can give you good ideas for better eating.

For Comfort's Sake

Caregivers play a crucial role in maintaining the comfort and emotional well-being of someone they care for at home. Consider the following:

Temperature – Be aware that your home may need to be kept warmer than usual, especially in the bathroom during bathing time. The person with Alzheimer's may need to wear more clothing or layers of clothing to be comfortable throughout the house.

Pain relief – Because the person with Alzheimer's may not remember that he or she had pain five minutes ago, you will need to observe patterns of behavior that suggest pain and give pain medications routinely. Paying attention to nonverbal pain cues such as grimacing or crying is important. Repositioning, massaging, and using pillows to support the extremities may ease pain for someone who is confined to bed or a chair for much of the day.

Nonverbal communication – Your presence, touch, gestures and attentive listening can communicate acceptance, reassurance, and love to the person with Alzheimer's disease. Nonverbal communication is listening with your ears, eyes, and heart. Connect by looking beyond your loved one's declining function and focus on the person within.

Discuss Wishes Early

Because communication and cognitive skills decline as the disease progresses, many caregivers, family members, and care providers must make decisions based on what they think the person with Alzheimer's disease would want.

Deciding what is best for the person you care for will be made easier if you can discuss the future while he or she is still able to communicate. Talk with the person with Alzheimer's disease as soon as possible about his or her wishes. Advance directives, such as a living will and a durable power of attorney for healthcare, provide the best means to voice preferences for medical care in case they lose the capacity to make such decisions or are unable to express their wishes. These documents must be prepared while a person is still mentally competent.

Caregiving decisions in the later stages are difficult. What do you do if the person you care for refuses to eat or drink? Would he or she want feeding tubes or intravenous hydration? Would he or she want to use comfort measures or treatments that prolong life?

In preparing to make such decisions, ask:

- What would the person for whom I care want?
- What is in the best interest of the person for whom I care?
- What are the person's cultural or religious values?
- If medical treatment is a possibility, what is the expected outcome and possible risks of the treatment?

An especially difficult decision may be determining whether a nursing home,

respite, or hospice care facility should be considered.

Before Time Passes

By working out such issues before a crisis arises, you can anticipate the needs of the person you care for and make informed decisions that are consistent with his or her desires.

For More Information

Contact the Alzheimer's Association 24/7 Helpline at 800-272-3900 for Late-Stage Care and End-of-Life Decision-Making brochures. We also offer the Living With Alzheimer's – Late-Stage program, either in person or online, at training.alz.org. For a list of local offerings, call the Helpline or visit alz.org/indiana. There is always a staff member available to help you process these difficult decisions.



Step 7: Plan Ahead for End-of-Life Decisions

Unfortunately, Alzheimer's and most other dementias are fatal diseases. When your loved one approaches the end of life, you must make difficult decisions regarding care. Ultimately, any end-of-life decisions made on the individual's behalf should respect his or her values and wishes and maintain his or her comfort and dignity.

Talk with the physician and other healthcare providers. Make sure healthcare providers understand the person's directives and are prepared and willing to carry them out. Work with the healthcare team to develop and monitor a plan of care based on your loved one's advance directives.

Talk with your family. Family members must also understand, respect, and abide by the person's wishes. Having a family meeting to discuss the person's wishes and work out issues may prevent conflict later or rushed decision making in a crisis situation.

Understanding Levels of Medical Care

Aggressive Care

Aggressive medical care is used in life-threatening situations and is intended to prolong life. Aggressive care measures include using:

- Respirators to take over breathing
- Feeding tubes and intravenous hydration when a person is no longer able to eat or drink
- Antibiotics to treat life-threatening infections
- Cardiopulmonary resuscitation to restore heartbeat and breathing

Feeding tubes and IV hydration –

Persons with late-stage Alzheimer's disease frequently develop eating and swallowing difficulties and lose weight. When a person refuses or is no longer able to eat or drink, decisions may need to be made about artificial nutrition and hydration.

Feeding tubes are sometimes used in response to a person's refusal or inability to eat. However, there is no evidence that tube feeding extends life, prevents infection, or has any other benefits. Tube feeding is also associated with higher levels of aspiration pneumonia, diarrhea, and physical restraint.

There are alternatives to tube feeding throughout the late stage of the disease, such as a conscientious program of assisted feeding. For the person who can no longer swallow, an approach focusing on comfort in dying is most appropriate.

Intravenous hydration may temporarily provide fluid but cannot maintain nutritional requirements. Increased hydration may also decrease the person's comfort because hydration promotes excessive respiratory secretions, resulting in breathing difficulties. The absence of hydration is a normal part of the dying process and allows a more comfortable death over a period of days. The use of intravenous hydration can prolong dying for weeks and physically burdens the person. If artificial means are used, families will eventually be faced with the tough decision about whether or not to withdraw such treatments.

Antibiotics – Pneumonia and urinary tract infections are also common in late-stage Alzheimer's. Antibiotics may be prescribed to treat those infections, but they need not be. Antibiotics may not improve the person's condition. However, other medications should always be used to treat the person's symptoms and maintain comfort.

Cardiopulmonary resuscitation and do not resuscitate orders – Families may have to decide whether medical professionals should try to resuscitate a person in the event of cardiac arrest. Cardiopulmonary resuscitation may be ineffective in prolonging the person's life, be painful and traumatic, and leave the person in worse condition. Most families request a do not resuscitate order be signed by the physician and placed in the person's medical chart, which states that no attempts will be made to revive the person. There is also a form to be kept in the home (in Indiana, the Out-of-Hospital DNR). Cardiopulmonary resuscitation is often not recommended by many knowledgeable medical professionals.

Conservative Care

Conservative care includes routine procedures, such as providing the medication to treat high blood pressure or diabetes.

Palliative/Comfort Care

Rather than focusing on a cure or prolonging life, palliative care emphasizes quality of life and dignity by keeping the person comfortable and pain-free until life ends naturally. Hospice programs provide palliative care to individuals in the final stages of terminal illness and support services to the family.

Hospice Care

Hospice is a model of quality compassionate care for people facing life-limiting illness and is tailored to the medical, emotional, and spiritual needs of the patient and the family. Hospice places an emphasis on maximizing symptom management and providing counseling and bereavement services to the family before and after their loved one dies. Hospice is most often provided at home but can also be done in a facility. It uses a team approach and includes a registered nurse, social worker, chaplain, certified nursing assistant, and volunteers. The service also includes medications related to the disease and medical equipment. The program does not offer 24-hour care in the home but is set up to be of assistance to the person's primary caregiver. Medicare has the "gold standard" in hospice care, and most other insurances go by this standard. To qualify for the Medicare Hospice Benefit, a physician must certify a prognosis of six months or less. Other criteria include maximum assistance for

all activities of daily living, no meaningful communication (speaking six words or less), incontinence, 10% weight loss, or history of infection in the past 12 months. The Alzheimer's Association Helpline, 800-272-3900, can provide information on hospice providers in your area. To learn more about hospice, visit nhpco.org (National Hospice and Palliative Care Organization).



"Although my wife is unable to walk, speak, or feed herself, a stuffed bear seems to have made a difference in her life now. This new and constant companion is soft and cuddly and responds with grunts to voices or other sounds. My wife holds her soft new friend with one or both arms most of the time and sometimes strokes his fur. Judging from her facial expressions and her grasp of the bear, my wife seems to be more relaxed and contented now that she has this companion."

Making Informed Decisions

Consider the following when making end-of-life decisions about your loved one's care:

Focus on the person's wishes. Compare any recommended medical treatments or actions against the person's wishes for care or what you believe the person would want. For example, does he or she want all available treatment measures or only specific ones? Does he or she want medication to ease pain but not fight infection?

Reflect on the person's values and beliefs. Cultural, religious, spiritual, and family values and beliefs often influence people's decisions to use medical treatments. These values and beliefs also affect definitions of quality of life and death. Let the values and beliefs of the person with Alzheimer's guide your decision making. Distinguish your values and beliefs from those of your loved one; they may not be the same.

Weigh the burdens and benefits of treatments. Talk with the medical care team to find out if the treatment will improve the person's condition or comfort and for how long. Find out if the treatment will pose excessive physical or psychological burdens. Compare any recommended treatments with the person's wishes for end-of-life care.

Make each decision separately. Advances in medicine and technology have made it possible to extend and, in some cases, improve a person's life. However, certain treatments may also lengthen the dying process and cause more complications and pain. You may agree to use a treatment for a limited time to see if it benefits the person.

Consider the location for care. Find out what treatments can be provided in familiar surroundings and what type of care may require a transfer to another setting, such as a hospital. In general, the temporary transfer to a hospital for tube placement or other interventions is disorienting and may be harmful to persons with dementia. Discuss with the care team if and when moving a person to a different setting is in his or her best interest.

Do not equate the refusal or withdrawal of treatment as assisted suicide.

This includes tube feeding, antibiotics, cardiopulmonary resuscitation, or more aggressive efforts. Treatment limitations allow for a natural course of the disease and promote the person's comfort and dignity. If treatment is refused or withdrawn, the person will continue to receive quality care.

Requesting a Brain Autopsy

Brain autopsy is still the only way to confirm that an individual had Alzheimer's disease or another type of dementia. Brain autopsy for Alzheimer's may require special arrangements, and the decision to have one should be made well before the person's death. To learn more about brain autopsy and making arrangements, call the Alzheimer's Association 24/7 Helpline at 800-272-3900.

For More Information

Contact the Alzheimer's Association 24/7 Helpline at 800-272-3900 for brochures on Late-Stage Care and End-of Life Decision Making. We also offer the Living With Alzheimer's Late-Stage program, either in person or online, at training.alz.org. Check for local offerings at alz.org/indiana or call the Helpline.

SECTION 3

CARING FOR THE CAREGIVER

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Caring for the Caregiver

How do you balance your own needs with the needs of the person with dementia? There is often a strong temptation to do everything possible for someone under your care at the expense of your own physical and emotional health. However, if your own well-being is neglected, the quality of care you provide may be jeopardized as well. Therefore, it is essential for you to remain healthy by learning to cope with the stresses of caregiving.

A report released by the Alzheimer's Association showed that Alzheimer's caregivers have a heavier burden than other caregivers due to the number of hours spent providing care, the duration of time they give care, and the difficulty of the tasks they perform, all of which lead to an increase in unmet needs and personal sacrifice for these caregivers.



"My wife attends daycare regularly.

She was unable to go for several days, so the day care center gave us a large box of buttons to have her sort. She was extremely content to work for hours at 'her job'."

- Most revealing, unpaid Alzheimer's caregivers make more personal sacrifices, such as giving up family time, friends, vacations, and exercise, to provide care.
- These caregivers also tend to have to perform more difficult types of tasks, such as dealing with incontinence, bathing, and feeding. These duties are done in addition to a full-time job for half of the caregivers in the study.
- Alzheimer's caregivers face challenges arising from their loved ones' cognitive impairment that are not faced by other caregivers.
- Behavioral issues created by Alzheimer's disease cause caregivers to face higher levels of stress associated with their loved ones' wandering and failure to remember to take medications.
- Caregivers face unique challenges and need more emotional and financial support and information.

Providing care to someone who is becoming increasingly dependent may require a change in priorities. This may appear to be an overwhelming challenge, but it is a challenge that is manageable with education and support. There are many ways of coping, and no single strategy works for everyone. Begin by learning about the disease. Check out books and videos on the subject of dementia and attend educational seminars. Review the resources listed at the end of this manual. Share this information with family and friends so they will know how best to provide support.



"Heather enjoyed old Shirley Temple movies on tape. Paul loved animals, and any animal/nature video gave him many pleasurable hours. Their caregivers then had time to do chores or just be by themselves."

10 Ways to Be a Healthy Caregiver

Find a physician or other healthcare professional who understands the disease and the impact it might have on you. Support groups where you will meet caregivers facing similar challenges might also provide guidance. The Alzheimer's Association offers both in-person and online support groups. Professional counseling might be beneficial.

As a caregiver, it is very important to have occasional breaks and to enjoy some leisure time. There are services available to care for loved ones while you take breaks, including in-home care and adult day care, which can allow respite for a few hours each week. This is important for your physical and mental health. Other examples of ways to take care of yourself include pursuing hobbies, becoming active in your community or church, and meeting regularly with friends.

Realize from the beginning that this is a difficult situation. It is likely that the disease will worsen in spite of all efforts. Nevertheless, take pride in the care and comfort you provide. Your commitment and hard work enable another person to live—and die—with comfort and dignity.

1. Get a diagnosis as early as possible.

Symptoms of Alzheimer's may appear gradually. It can be easy to explain away unusual behavior when your loved one seems physically healthy. Instead, consult a physician when you see signs of the disease. Don't delay; some symptoms are treatable.

2. Know what resources are available.

Get in touch with the Alzheimer's care resources in your community. Call the Helpline at 800-272-3900 to receive a Resource Guide for your area, or visit communityresourcefinder.org.

3. Become an educated caregiver.

As the disease progresses, new caregiving skills are necessary. The Alzheimer's Association can help you better understand and cope with the behaviors and personality changes that often accompany Alzheimer's progression.

4. Get help.

Doing everything by yourself will leave you exhausted. Seek the support of family, friends, and community resources. If you're afraid to ask for help, have someone advocate for you. The Helpline and support group meetings are good sources of comfort and reassurance. If stress becomes overwhelming, seek professional help.

5. Take care of yourself.

Watch your diet, exercise, and get plenty of rest. Make time for shopping, a movie, or an uninterrupted visit with a friend by taking advantage of community services like adult day care or in-home services.

6. Manage your level of stress.

Stress can cause physical problems (blurred vision, stomach irritation, high blood pressure) and changes in behavior (irritability, lack of concentration, loss of appetite). Note your symptoms. Use relaxation techniques that work for you and consult a physician.

7. Accept changes as they occur.

People with Alzheimer's change and so do their needs. They often require care beyond what you can provide on your own. A thorough investigation of options, from home and community-based services to residential care, should make transitions easier. The support and assistance of those around you will also help you accept change. Use the Helpline to help determine the best course of action in each stage of the disease.

8. Do legal and financial planning.

Plan ahead. Consult with an elder-law attorney to discuss legal and financial issues, including durable power of attorney, living wills and trusts, future medical care, housing, and long-term care insurance. If possible and appropriate, involve the person with Alzheimer's and other family members.

9. Be realistic.

Know that the care you provide does make a difference. Also know that until a cure is found, Alzheimer's disease will progress. Many of the behaviors that occur are beyond your control and the control of the person with Alzheimer's. Give yourself permission to grieve your losses, but also focus on the positive moments as they arise. Enjoy your good memories.

10. Give yourself credit, not guilt.

At times, you may lose patience and find yourself unable to provide all of the care the way you'd like. Remember, you're doing the best you can. Don't feel guilty because you can't do more. Your loved one needs you, and you are there; that should make you feel proud.



Some Advice on Stress Management

Stress is not necessarily bad; it is a normal part of our lives. Stress is a dynamic tension that produces a force capable of accomplishing a movement or task. When stress becomes a constant in our daily lives, it transforms into distress. You want to manage the physical and emotional stress in your daily life — so that it does not become distress — so that YOU do not become distressed.

Do not ignore signs of distress within yourself:

- Anxiety, worry, short temper, irritability
- Headaches, backaches, tense muscles
- High blood pressure, digestive disorders
- Restless sleep

Letting the stress develop into distress compounds the challenges, both for you and for the person for whom you are caring. Give yourself the gift of learning how to respond to stress in healthy, productive ways before it becomes distress.

Let's be realistic: Physical and emotional stress can become constant when caring for a person with Alzheimer's disease. Experiment with different stress management techniques to discover what will work best for you at any given time.

The person you are caring for cannot change his or her condition. However, you can decide how you react to the daily situations that arise.

Consider these stress management techniques:

- Pause frequently throughout the day, take some deep breaths, and allow your body's muscles to relax.
- When your loved one is napping or otherwise not requiring your attention, give yourself 20 minutes for an enjoyable activity.
- Join a support group and ask how others cope with and manage their stress.
- Get some help with household chores, yard work, shopping, and caregiving.
- Eat nutritious meals.
- Treat yourself to a massage.
- Step outside and notice the weather, look at the sky, and connect with nature.
- Get enough sleep and rest.
- Talk with a friend who can provide useful and productive feedback.

About Support Groups

Support groups are designed to provide opportunities to learn from other participants how to deal more effectively with the challenges of caregiving. There may be anywhere from three to 15 people in a group at any given session. They generally last for an hour and a half.

Groups have an open-discussion format where participants present specific questions and situations. They will often receive feedback from others who may have similar experiences and offer insight and helpful tips. Some participants attend regularly for years. Others will attend occasionally when they have a specific need.

Alzheimer's Association support groups have a code of ethics:

- Confidentiality: What is said there, stays there.
- Politics are not discussed.
- Religion is not discussed.
- No product endorsements are allowed.
- No fees are charged.
- The environment is safe for sharing.
- Participants learn how to listen and respect each other's situations.

Alzheimer's Association support groups are good sources to share:

- Tips and techniques that have helped others
- Information on other resources you will need
- Emotional support

Alzheimer's Association support groups can:

- Be a place to find new friends
- Help you get through some of the worst times
- Save you wasted time, effort, and frustration
- Allow you to participate as a listener
- Provide humor, which has many benefits
- Help you recognize signs of stress that you fail to notice yourself

Find a support group near you by calling the Helpline at 800-272-3900 or visit alz.org/indiana for a complete listing. Connect with other caregivers and individuals with Alzheimer's disease online through ALZConnected® at alzconnected.org.

"Support groups are for those touchy-feely people... I don't have time for that."

Bernie was struggling with learning how to deal with everything, as his wife moved deeper into the challenges of Alzheimer's disease. Thinking that the Alzheimer's Association support group was some sort of "emotional release workshop," he gave little thought to attending.

Then he started hiring caregivers, and realized that he needed some help learning how to select, train and manage them. He called the Alzheimer's Association Helpline to find out if there were any classes on that topic. The Helpline specialist told Bernie that the caregiver's support group devoted a lot of attention to that matter. He decided to give it a try and went to a meeting.

Bernie has since become a strong supporter of, and recruiter for, Alzheimer's support groups. He learned that the people attending his group were able to give him ideas, information, coaching and encouragement over the years that followed. Looking back, Bernie wonders how he ever would have been able to manage his wife's care without the support group.

Using Substitute Care

What Is Respite?

Pronounced res'pit, it means a time of rest and relief.

Respite care may be provided by:

- Friends
- Relatives
- Volunteers
- In-home companion sitters
- Adult day centers
- Nursing homes
- Professional caregivers

Along the way, many caregivers have learned that their loved ones often fair quite well with strangers. Strangers are not as emotionally involved as family members and can offer a fresh experience for the person with dementia.

Even though it may be challenging to leave your loved one for this purpose, it is in his or her best interest that you give yourself an opportunity to refresh. Respite can help you strengthen your mind, emotions, and physical health.

Rather than waiting until you are near the breaking point, discipline yourself to schedule such breaks on a regular basis.

What Is an Adult Day Center?

Adult day centers are programs that offer socialization, activities, and meals in a safe, supportive environment.

Who attends an adult day center?

- Someone with Alzheimer's disease or another dementia
- Someone who needs supervision during the day
- Someone with physical or mental limitations
- Someone who may be socially isolated or lonely and feels more comfortable in a supervised setting

Why use an adult day center?

- Adult day centers allow the caregiver an invaluable source of respite.
- They provide socialization and activities for the person with Alzheimer's disease.
- The setting provides a safe, nonjudgmental place for people to feel at home and remain active, social, and independent.

Find respite and adult day centers among other area resources on our Community Resource Finder, a simple online search tool at communityresourcefinder.org



NOTE: Cost, hours of operation and some services (such as transportation) vary between adult day centers. Call the Alzheimer's Association Helpline to find the adult day center nearest you. Sometimes persons with dementia can become hesitant, even resistant to the idea of going to a "day care" center. Calling it a social center, senior center or volunteer center may relieve the tension. Work with the staff to find a specific task or activity that will help them feel more at ease. Establish a routine that works for both of you and "if at first you don't succeed ... try, try again!"

Acknowledging Spiritual Needs

Caregivers are people who know hunger and hope. All people have spiritual needs. Even if they do not belong to a church, identify with a particular religion, or profess faith in God, most people have a need to find meaning in life. People search for ultimate meaning — for a relationship to something bigger than themselves.

Ernest Becker, in his book *Escape From Evil*, defines spirituality as “an expression of the will to live, the burning desire of the creature to count, to make a difference on the planet because he has lived, has emerged on it and has worked, suffered and died.” This desire to make a difference may serve as a source of strength and motivation for caregivers. It is not unusual to hear caregivers say, “I may not be able to change the world, but I can affect what goes on in my little corner of it.”

Spiritual Needs of Caregivers

By viewing caregiving as an opportunity rather than a burden, the stresses of providing care may diminish. The spiritual need for peace and harmony is enhanced when people have inner strength. If care is provided primarily out of a sense of duty or obligation, the burdens and stresses can seem great. The commitment to caring for the person with Alzheimer's is often made again and again. Each time the decision is made, you must assess both the needs of the person with Alzheimer's and your own internal resources. Do you have sufficient inner strength to offer care with a minimum amount of distress?

One of the chief aspects of spiritual well-being is self-knowledge. All people need to be recognized, appreciated, and loved. All people need social interaction. When you assume the role of caregiver, those needs do not disappear. Self-knowledge will enable you to be aware of how much recognition, appreciation, love, and social interaction you need or can expect from others.

It is wise to remember that people who choose to be caregivers do so with a complex set of motivations. Some of these motivations are viewed as admirable and altruistic. Love, loyalty, duty, self-sacrifice, and familial or religious obligation are often among the motivators. Low self-esteem, financial need, rigidity, fear, habit, and self-punishment may also be among the motivators.

Positive and negative motivations can be present at the same time. Self-knowledge that leads to an awareness of your own needs, values, limitations, and complex motivations may be the first step in enabling you to see these factors as opportunities for continued growth.

Caring for someone with Alzheimer's can cause a wide range of feelings in the caregiver. The acknowledgment of those feelings is an activity of the spiritual life. Some feelings that arise again and again are helplessness, anger, guilt, loneliness, joy and delight, sorrow and loss.

Alzheimer's disease can raise the question “why did this happen?” Asking why is appropriate and necessary. But, eventually, the question no longer serves the questioner, and a decision must be made to abandon the cycle of

blame, helplessness, and self-pity that it generates. Energy can then be redirected to problem solving and coping. The decision to live with certain mysteries in life is a spiritual one that will likely lead to harmony and peace.

Spiritual Needs for the Person With Dementia

The seeds of spirituality are sown in childhood. Long before children have words to describe feelings, they know what it is like to be loved or they know the loneliness of not having someone care for them. These feelings are stored in the long-term memory and can be tapped even in late stages of dementia. Many people with dementia are also able to respond to religious or spiritual symbols and rituals from their childhood. Old memories may be stirred up by participating in religious activities.



You can help the person tap into their spirituality in these ways:

- Take a walk in the woods together and appreciate nature's wonders.
- Listen to moving music or favorite religious hymns.
- Read familiar scripture passages or prayers.
- Enjoy objects of beauty or religious significance.

In addition to tapping into remembered faith, caregivers need to be attentive to the issues of grief and loss that confront the person with dementia. Acknowledge the person's feelings of sadness and loss while focusing on his or her remaining abilities. Caregivers contribute to the spiritual well-being of their loved ones when they promote empowerment and respect.

Everyone has a need to be heard. Listen to the verbal and nonverbal concerns of the person with Alzheimer's and allow him or her to express anger — even anger at God. Frequently, caregivers and the people they care for try to protect one another from the pain each feels. The result is further isolation. The sharing of an experience that is a source of spiritual nourishment can break down isolation. Read together significant spiritual passages from the Bible for their religious meaning or literary references that convey profound feelings about the human condition.

Grief and Loss

If you are a caregiver, you may have feelings of loss and grief as your life and the person you love are changed by Alzheimer's disease. These feelings are difficult, but they are normal. Everyone grieves differently and at their own pace. If your grief is so intense that your well-being is at risk, do not be afraid to ask for help from your doctor or a professional counselor.

No two people grieve the same way. Think about your feelings, both the positive and the negative. Let yourself be as sad as you want to and accept your feelings of guilt. These are normal feelings. You may experience feelings of loss throughout the disease process and as the person continues to change. It is okay and normal to have feelings of love and anger at the same time. If you are having a hard time expressing your feelings, consider starting a caregiving journal.

Some symptoms of grief include:

- 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 disease and with caregiving tasks
- Withdrawal from social activities, friends, family, and the person for whom you care



Guilt

Throughout the grieving process, guilt can be a prevalent feeling 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 one has been transitioned to a long-term care facility
- Negative thoughts about the person with the disease, including 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 is being provided
- Unrealistic expectations that you place on yourself and thoughts that "I must be perfect" or "I must do everything"

Try different coping strategies:

- Accept and acknowledge your feelings.
- Accept that some things are beyond your control. You can make responsible decisions about things you can control.
- Think about the fond memories you share with the person.
- Remember that you do deserve good things and positive feelings.
- Get involved in activities that interest you.
- Turn to your spiritual beliefs for consolation.
- Talk to others. Share feelings with family and friends. You may want to talk with a professional who specializes

in grief counseling.

- Call the Helpline anytime at 800-272-3900.
- Do things you enjoy. Caregivers often give up enjoyable activities and companionship.
- Take a break. It may help you relive stress and grief and strengthen your support network.
- Learn to feel comfortable accepting and celebrating good things in your life.
- Forgive yourself.

More resources on grief:

Alzheimer's Association 24/7 Helpline
800-272-3900

Indiana Association for Home and Hospice Care
hhpco.org
317-844-6630

Indiana Crisis Hotline
317-251-7575

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SECTION 4:

GUIDELINES FOR PROVIDING CARE

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Ensuring Personal Hygiene

The person with dementia may eventually need assistance with bathing, grooming, and dressing. Since these are usually private activities, the person may refuse help. With a calm, matter-of-fact approach, you can usually get cooperation. Allow them to do as much as they can independently. Lead, guide, and assist when necessary.

Bathing

Keeping the person with Alzheimer's disease clean and well groomed can be a challenge. A depressed person might have lost the desire to bathe, while another person might feel embarrassed about getting undressed or might become frightened by running water, temperature changes, or mirrors.

Refusing to bathe may be caused by a variety of issues:

- Forgetting how to feel safe with water
- Loss of visual/spatial perception (where is the bottom of the tub?)
- Being in a small room and feeling trapped
- Being cold, confused, and uncomfortable with not being able to control the temperature of the shower spray
- Feeling ashamed of being naked in front of someone else, regardless of who it is
- Afraid of slipping or falling
- Not being agile and able to move comfortably through the process of washing and drying

Forgetting the sequence of the bathing process

For the person who has Alzheimer's, it's easy to feel confused and overwhelmed by simple daily routines such as bathing and grooming. If the person seems afraid, stressed, or resistant to bathing, try to determine the reason by asking yourself the following questions:

Physical/Psychological Factors

- Does the person seem depressed?
- Is there a physical illness or infection?
- Does the person seem overly sensitive to water or changes in water temperature?

Environmental Factors

- Is the person sensitive about having someone else in the bathroom?
- Is the person able to find the bathroom and see clearly?
- Is the room temperature too cold?
- Is the water temperature too hot or cold? Is the water pressure too intense? Is the water in the tub too deep?

Special Concerns

- Is the person afraid of falling, running water, or soap?
- Is the person confused by such tasks as turning on the water or filling the sink?

Once you've determined the answers to these questions, you'll be in a better position to manage the bathing routine.

Some Things to Try/Steps to Take

Have reasonable expectations – Frequency of washing and bathing is a personal preference. Some people may not feel the need to shower and/or wash their hair every day. In these cases, you might want to alternate a sponge bath with a more complete bath or shower.

Adapt to the person's needs, routines, and preferences:

- Daily bathing is not always necessary and may be damaging to fragile skin. Washing the person's face, hands, and genital area may be all that is essential daily.
- Remember that bathing may be accomplished by bath, shower, or sponge bath, and it is not always necessary for it to happen in the bathroom.
- Avoid discussion of the need for a bath or shower. Be matter-of-fact: "It is time to take a bath."
- If the person is used to taking a shower in the morning or a bath at night, try to maintain that routine. Changing that routine might distress the person.
- Remember that a person with Alzheimer's disease may refuse to bathe for an unfamiliar caregiver of the opposite or same sex.
- If the person is too modest to be seen naked, let them stay wrapped in a towel or wear a swimsuit. A shower bench or chair will be helpful as well.

- Do not schedule a bath or shower at times that are already stressful for you or the person. Pick a time when you are least likely to be interrupted. Leaving a confused or frail person alone in the tub or shower can be frightening and dangerous.
- If you have access to a Jacuzzi or spa tub, the person might find that to be more appealing than a conventional bath or shower.
- Try joining the person in the tub.
- A back rub with lotion may convince the person that a bath is not all that bad.
- Say, "The doctor says you must bathe every Tuesday. Today is Tuesday."
- Some adult day centers will provide baths and can be less frightening.

For more information on organizing your daily routine, visit alz.org/care/dementia-creating-a-plan.asp



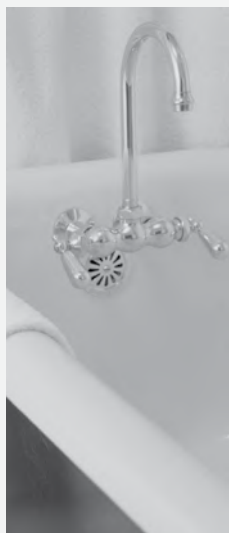
"My husband refused to let me wash his hair. A barber suggested brushing aftershave lotion into his hair and then drying his hair with a towel. He explained that the alcohol in the aftershave breaks down the oil in the hair."

Prepare the bathroom in advance:

- Have the towels ready.
- Draw the water in the bathtub and test the temperature.
- Pre-measure the shampoo.
- Develop a soap pocket in the washcloth so that washing one's self is possible.
- Keep the bathroom warm and comfortable.
- Have warm, dry clothes ready.

Gently prepare the person for the bath

Be direct at bath time by using such phrases as "your bath is ready." In this way, the person will focus on each step of the task instead of whether or not a bath is needed or wanted. If the individual continues to resist the idea of bathing, change the subject and then try again.



"Hillary coaxed her husband into the tub, but when she tried to wash his genitals, he took a swing at her. She gave him a washcloth to hold. He got it sopping-wet and tossed it toward the stool. She retrieved it. He again tossed it. This time when she retrieved it, she caught a devilish twinkle in his eye. They both laughed and finished the bath."

Make the bathroom safe:

- Always check the temperature of the water. The person may not be able to judge temperature.
- Avoid using bubble bath or bath and shower oils that would make the tub or shower stall slippery (a walk-in shower is safest since it prevents needing to step over a tall tub wall).
- Showers are often more dangerous and frightening to people with Alzheimer's disease than baths. If you must use a shower, install grab bars and use a tub seat.
- Never leave a person alone in the bath or shower.
- Consider using a handheld showerhead.
- Use only two to three inches of water in the tub and make sure there are rubber mats or decals on the tub's bottom.
- Use a nonslip bath mat and make sure that the bathroom floor is free from puddles. Some caregivers install carpeting in the bathroom.
- Remove electric hairdryers and razors.

Take care in giving the bath:

- Allow the person to do as much as possible without your help.
- If the person is frightened, distract them with conversation.

- Gently coach the person during each step of the bath, reminding the person of the areas that need washing. You may need to complete part of the bath or shower yourself.
- Plan to do a project such as hair washing in the morning when the person is well rested. Get the individual to participate as much as possible.
- Avoid using harsh deodorant soaps unless there's a serious problem with incontinence, in which case there are special soaps available.
- Make sure that the person washes the genital area, especially if incontinence is a problem. Also, make sure that the person washes within folds of flesh and under the breasts.
- After the bath or shower is completed, be sure that the person is completely dry.
- Check the person for red areas of skin, rashes, and sores. If the problem is serious, consult a physician. Pressure sores and skin ulcers can develop quickly on people who sit or lie down much of the time.
- Use a body powder, cornstarch, or baby powder under the breasts, in creases or folds of the skin. Use lotion to keep skin soft and pliable. If the individual resists deodorant, try baking soda.

Above all, do your best to maintain the person's dignity. You may need a home health aide to help with bathing. When the time comes, the Alzheimer's Association has a list of home health agencies.



"When right and left began confusing my wife as she dressed, I would hand things to her one at a time, in the proper order."

Dressing

With increased memory loss, the steps involved in getting dressed become more difficult for the patient to handle alone.

- Allow the person to dress independently as long as they are able to, regardless of how long the process takes.
- Give step-by-step instructions, allowing the person to finish one step before continuing on to the next.
- Lay out clothes in the order they will be put on. If necessary, hand each item of clothing to the person one at a time.
- You may find it helpful to describe to the person what you are doing as you do it. For instance, say, "It's time to get dressed now. Here is your shirt."
- Clothing should be comfortable and loose fitting.
- If shoelaces, zippers, buttons, and buckles are difficult, consider using slip-on shoes (ones that won't slip off easily), elastic shoe laces, sneakers with Velcro closings, pants with elastic waist bands, clothing that closes in the front and has Velcro tape or large zipper pulls.

- Keep only seasonal clothes in the closet or keep the closet locked and put out one outfit at a time.
- Give the person a choice of two tops (or slacks, dresses, etc) to encourage independence.
- If the person insists on wearing the same clothing day after day, try buying several duplicate sets of the same clothes and rotating them
- If incontinent undergarments are used, remove the opportunity to choose underwear.
- Continue to visit the barber shop/ beauty salon regularly, but call ahead to inform them of diagnosis and allow extra time if needed.
- Some hairdressers will make home visits.
- To reduce waiting and confusion, ask for the first or last appointment of the day.

Grooming

Good grooming helps to maintain the person's sense of self-worth.

- Encourage the person to groom independently for as long as possible.
- Guide and assist the person as needed. Give step-by-step instructions, allowing the person to finish one step at a time.
- Keep fingernails and toenails clean and cut short (visit a podiatrist or a beauty school if necessary).
- For men, encourage daily shaving with an electric razor. Use a pre-shave softener to help reduce pulling and razor burn.
- For women, continue a normal makeup routine if practical.
- Short hair is usually easier to manage than long hair.

"A caregiver bought one of those new kinds of toothpaste with the pump, figuring that it would be easier for his wife to use. He gave it to her and she just kept insisting that it wasn't toothpaste."



"My wife has dentures. I didn't know how to remove them from her mouth, so I asked the dentist to show me."

Oral Hygiene

Poor oral hygiene can lead to infection, gum disease, or toothaches.

- Demonstrate the steps of brushing; allow the person to imitate one step at a time.
- If you start the motion, the person's lifelong habit may take over. Try guiding the hand that is holding the toothbrush until the person takes over.
- Brushing your teeth at the same time may help them feel more comfortable.
- Dispense toothpaste as needed rather than leaving the tube out.
- If the person wears dentures, you may need to supervise the cleaning process and see that they fit properly. Poorly fitting dentures make it difficult to eat and digest food.
- Try using a long-handled or angled brush or electric toothbrush if you are doing the brushing.
- Be aware of medications that cause dryness of the mouth. Frequent mouth rinses can help a dry mouth, but avoid commercial rinses that contain alcohol, which contributes to dryness.
- Do not keep any other tubes on the bathroom sink, as they can be mistaken for toothpaste.
- In the later stages, mouth swabs or Toothettes can be used to keep the person's teeth and mouth clean.

Nutrition

A balanced diet is essential for good health. It helps avoid dehydration, constipation, malnutrition, or other illnesses and promotes a sense of well-being.

- Be sure the person eats a balanced diet and drinks at least six cups of liquid daily. It is important that the foods offered meet any medical requirements, especially if the person is on a low-fat, low-salt, diabetic, or other restricted diet.
- Rather than argue with a memory-impaired individual about foods that they should avoid for health reasons, avoid having tempting but unhealthy foods in the house, or store them in an inaccessible place so that you can control how often they are eaten.
- If weight gain is a problem, try serving smaller portions or small, frequent meals, substituting nutritious snacks for high-calorie junk food. Also, try increasing the person's level of exercise.
- If the person is losing weight, consult a medical professional. There may be problems with absorption of food or other medical problems.
- If the person is eating poorly and is otherwise in good health, a nutritional supplement may be needed.
- If cooking is difficult for the caregiver, explore a home-delivered meal program.
- Try to avoid caffeine, especially later in the day.

Mealtime

Although most individuals with Alzheimer's disease do not need special diets, they may develop eating problems that make it difficult to ensure that proper nutrition is received. Dehydration is also a danger for the person with dementia who loses the sense of thirst or simply forgets to drink.

Tips for Successful Dining

- For easy swallowing, the person should be sitting with his or her head slightly forward, not backward.
- Soft, thick food is less likely to cause choking than pieces of food that are slippery or require a lot of chewing.
- Do not feed a person who is drowsy or agitated.
- Do not feed a person who is lying down.



- If restlessness makes it difficult for the person to stay seated for an entire meal, try smaller, more frequent meals, or serve finger foods that will allow the person to eat while moving around.
- Eating problems may stem from treatable causes, such as poorly fitting dentures or a sensitive tooth. Try to maintain a calm, relaxing atmosphere at mealtime.
- A person who has been accustomed to cooking may enjoy helping with meal preparation. Depending on the level of functioning, appropriate tasks may include stirring food, setting the table, folding napkins, wiping the table, and washing dishes.
- Serve meals at a regular time at the same table. Have the memory-impaired person sit in the same place at the table.
- Use a plastic tablecloth.
- Wearing an apron helps protect clothes from spills.
- Buy a plate guard at the drugstore to fit over the edge of the plate. This makes it easier for the person to put food on the fork and keeps the food from falling off the plate.
- It may be easier to use a bowl instead of a plate.
- To avoid spills, do not fill glasses or cups to the top. Clear glass or plastic may be difficult to see. Try using a spill-proof cup or a mug with a large handle.
- Allow the person enough time to eat.
- You may need to demonstrate how to use utensils. A spoon may be easier

to use than a fork or knife. Serving finger foods (sandwiches or cut-up vegetables) avoids the need for utensils.

- Use foods the person prefers and is accustomed to; new foods may cause confusion.
- Colorful, aromatic, and flavorful food may enhance the person's appetite.
- It may be helpful to serve one food at a time. Choices can be difficult. Encourage the person to eat slowly and chew one mouthful at a time. Instruct him or her to swallow after each chew if he or she is chewing too long. Use nonverbal reminders if needed.
- Keep the person sitting up for 20 minutes after eating. If a person lies down too quickly, food just swallowed may come back into the throat causing choking and possibly death.
- If any eating or swallowing difficulties are noted, call the physician for a home speech therapy evaluation to determine the cause and if any adaptive equipment is needed.
- Always watch for signs of choking.

Suggestions for Finger Foods

- Chicken nuggets
- Fish sticks
- Grilled cheese sandwiches (cut up)
- English muffins, toast
- Hard boiled eggs (quartered)
- Fried vegetable sticks
- Pork or beef (cut in small pieces)

Washing Up After Meals

- Fill a small plastic basin with warm sudsy water.
- Have the person soak his or her hands (this can be very relaxing).
- After massaging and washing the hands, clean and clip nails (if needed) and pat dry.
- A calm environment can make mealtime relaxing for both of you.
- Use hand sanitizer if washing hands is not an immediate option.

"Dee announced one day that she would drink coffee, which she loved, and that she 'was never going to eat again.' Her caregiver fixed her several cups of decaffeinated coffee a day: with 75% chocolate flavored drink, 25% coffee. After five days, Dee started eating solid food again as if nothing had happened."



"When matching dishes puzzled her while putting them away, I would ask my wife to hand them to me one at a time."

How to Handle Eating Problems

- Check the person's mouth, gums, and teeth or dentures.
- Watch for signs of irregular bowel movement and constipation.
- Try a complete, balanced nutrition/protein drink. If the person does not like it, try a different brand, type (rice, soy, egg, whey, etc) or flavor. Try mixing it in a milkshake with ice cream or fruit juice. (Read the labels carefully and compare different products. Some have significantly more nutritional values than others.)
- Puree cooked vegetables and grains in the blender or food processor.
- Offer finger foods such as raw vegetables, crackers and cheese, dried and fresh fruit, and toast and jam.
- Keep offering fluids such as water, and fruit and vegetable juices.
- Use wine glasses and make a toast.
- The person may want extra attention; not eating can accomplish this.
- If an eating problem persists, there may be an underlying medical problem. Discuss this with the person's physician.

Toileting

As memory loss progresses, individuals lose the ability to use the toilet alone.

If the person needs to use the bathroom, verbally remind them where it is or point; lead them there if necessary. Use a night-light in the bathroom.

- Restlessness or pulling at clothes may indicate a need to use the toilet.
- Learn the terminology that the person uses to state the need to use the bathroom.
- Make a trail from common resting places to the bathroom with thick painter's tape clearly marking the bathroom.
- Mark the bathroom with a sign or a picture of a toilet, or paint the bathroom door a bright color.
- If necessary, bring the toilet closer to the individual; use a portable commode or urinal.
- For safety's sake, remove the lock from the bathroom door.
- An elevated toilet seat and grab bars may be helpful to prevent falls (a home health therapy evaluation can determine if adaptable equipment is needed).
- Paint the wall behind the toilet a contrasting color.
- Put the trash can out of sight. It can be mistaken for the toilet.
- Toileting will be easier if clothing is simple. Avoid belts; use pants with elastic waists, such as sweat pants that are comfortable, nonbinding, and easy to take on and off.

- Encourage independent toileting. If assistance is needed, do not provide more help than is necessary. Start with verbal cues and gestures before helping with clothing, positioning, wiping, and readjusting clothing.
- If necessary, stimulate urination by running water or giving fluids to drink.
- If the person is no longer able to properly wipe, it must be done by you because of the risk of infection. Using rubber/disposable gloves may help.
- Limiting fluids in the evening can reduce the need to use the bathroom at night.
- Encourage fluids through the day; they are necessary for good health.

Constipation

Forgetfulness, poor diet, inadequate fluids, lack of exercise, and certain medications may contribute to constipation.

Watch for the following signs of constipation:

- Abdominal pain or bloating
- Headaches
- Restlessness or increase in agitation
- Frequent trips to the bathroom
- Straining

Things to consider:

- Some medications can cause constipation. Talk with the person's doctor if you suspect medication may be causing or contributing to this problem.
- In order to prevent constipation, the

person's daily diet should include exercise, plenty of liquids, and foods containing fiber and roughage (figs, prunes, prune juice, whole grain breads, cereals, pasta, fresh fruit, and vegetables).

- To avoid impaction, discuss with a health professional the use of a stool softener or agents that add bulk to the stool.
- Remember that it is not necessary to have a bowel movement every day.

Incontinence

Incontinence refers to the loss of bladder or bowel control. The medical term for loss of bladder control is enuresis. Encopresis is the term for loss of bowel control. Stress incontinence may follow laughter, coughing, lifting, or any sudden exertion.

Tips for managing incontinence:

- Incontinence may be a correctable problem. A medical evaluation is the first step in dealing with this problem.
- Sometimes incontinence results from a person's inability to find the bathroom or undress quickly enough.
- Keep track of bowel movements in order to learn the person's pattern, if there is one. This will help avoid accidents.
- Do not cause dehydration by restricting daytime fluids in an attempt to prevent incontinence.
- Remember that the person might not recognize the feeling of needing to go to the bathroom.

- If there is no medical cause for frequent urination, establish a regular toileting routine every two hours (upon rising, before and after meals, and at bedtime). If necessary, distract the person from toileting at other times.
- Praise successful performance; do not punish mistakes.
- Keep the genital area clean and dry to avoid infections and discomfort. Baby wipes are effective for this purpose.
- Use adult sanitary briefs, adult diapers, or other incontinence products if needed. Baby diaper doublers — available in some drug stores and supermarkets — can extend the life of more expensive adult diapers.
- Don't forget to request a senior citizens discount if eligible when purchasing incontinence supplies. Medicare might pay for these items.
- For the bed, use plastic sheets or disposable bed pads.
- On chairs, use washable chair cushions or towels over plastic cushions.

Sleep Problems

Changes frequently occur in the sleeping patterns of a person with a dementing illness. Sleeplessness at night is a common feature of Alzheimer's disease. This and other changes can be very stressful for the caregiver. As a result, you — the caregiver — experience sleep deprivation, too!

- Maintain a consistent and soothing bedtime routine and a regular wake-up time.
- Avoid daytime naps if the person has trouble sleeping at night.
- Encourage daily exercise.
- Evaluate any physical or emotional problems that may be contributing to sleep difficulties, such as pain or depression.
- Medications, including over-the-counter drugs, may affect the sleep-wake cycle. Consult a doctor or pharmacist if you suspect the person's medication may be contributing to a problem with sleeping.
- Avoid fluids after dinner, particularly those with caffeine.
- Have the person use the toilet before going to bed.
- Use a night-light if helpful.
- The use of sleep medications or tranquilizers can be considered if other approaches are not effective. However, these drugs may cause extreme drowsiness during the day and must be used with caution. Consult the person's doctor before using any over-the-counter sleep medication.

- Keep to as normal a routine as possible for as long as possible. Eventually it may become necessary to allow the person to sleep wherever he or she is comfortable, perhaps on a couch or recliner.
- Go to bed as the sun goes down and get up with the sun to keep the person's circadian rhythm.

Difficulties at Night

Your loved one may have trouble sleeping at night for a variety of reasons.

Here are some of the many possible causes:

- Too warm or cold; hunger or thirst
- The person's brain is no longer able to regulate the "body clock"
- Incontinence and/or bed wetting
- Troubling dreams
- Not enough exercise during the day
- Too much napping or inactivity during the day
- Confusing night with day
- Thinking it is time to get up and dress for work or prepare to take a trip

Pressure Sores (Bed Sores or Decubitus Ulcers)

Pressure sores first appear as reddened spots over bony areas and develop into open sores. They occur when a person stays in the same position too long and are more difficult to cure than to prevent. The most common areas for pressure sores are the base of the spine (tailbone), shoulder blades, and heels. The problem is more likely to occur if the person is very thin and either bedridden or chair-bound.

- Good nutrition and exercise promote circulation and reduce the likelihood of developing bed sores.
- Use of protective aids, such as a soft bed and chair cushions, lambskin, or an egg-crate foam mattress pad, help to prevent pressure sores.
- If the person is bedridden and unable to turn over, change his or her position every two hours. Turn the person from side to side and use pillows for support.
- If the person is confined to a chair for long periods, help the person stand and, if possible, walk at least every two hours.
- Use loose clothing made of soft fabric to reduce friction and pressure on the person's skin.
- Massage bony areas often with lubricating lotion.
- Check skin daily and document any red areas.

Activities

Creating an atmosphere of quiet activity in the home promotes the feeling that the person with Alzheimer's disease continues to be an important member of the household. Restlessness decreases, and life is more enjoyable for everyone.

- Some activities, such as cooking, gardening, raking leaves, and simple household chores, may help the person feel involved in what is happening around him or her.
- Helping with chores makes him or her feel like he or she is contributing to the household.
- Tasks that do not require much supervision give the caregiver a break.
- Do not ask the person to do a simplified version of an activity or craft in which he or she once excelled. The awareness of the loss of skills may be painful.
- Try to include some form of exercise in each day's activities. Walking, throwing a ball, or playing with a pet are simple activities that provide exercise.

Remember that the person's ability to perform a certain task may vary from day to day or moment to moment.

Activities that provide an opportunity for self-expression include:

- Dancing
- Singing
- Playing a musical instrument
- Drawing or coloring
- Painting
- Working with nontoxic clay

The following activities can be valuable if they are entertaining to the person:

- Car rides
- Excursions to the zoo/garden/pet shop/art museum
- Listening to music
- Playing cards/table games/simple puzzles
- Watching sports

Certain activities that involve reminiscing help promote a feeling of well-being. These include sorting or looking at old photographs, looking at picture books, or playing records from earlier years.

Remember:

- A person with Alzheimer's disease is likely to have a short attention span.
- There may be little creative capacity and ability to initiate activities. You may need to provide things to do.
- Activities that call for making choices or decisions may cause stress.
- Be creative and experiment with new approaches.

Call the Helpline at 800-272-3900 and ask for the "101 Things to Do with a Loved One with Alzheimer's Disease" fact sheet.

Activity Ideas

A good variety of activities can be both stimulating for the person with Alzheimer's disease and can be a diversion or help to the caregiver. A balance between household and leisure activities will include social, physical, cognitive, and spiritual activities.

Household activities –Washing dishes, sorting mail, clipping coupons, sorting socks, folding laundry, sweeping the floor, polishing shoes, raking leaves, weeding the garden, watering plants, rolling dough, snapping green beans, sorting recycling materials, and sorting cards are fairly simple work activities that can be done independently or with some assistance. When the person with Alzheimer's disease engages in these activities, express thanks for their assistance.

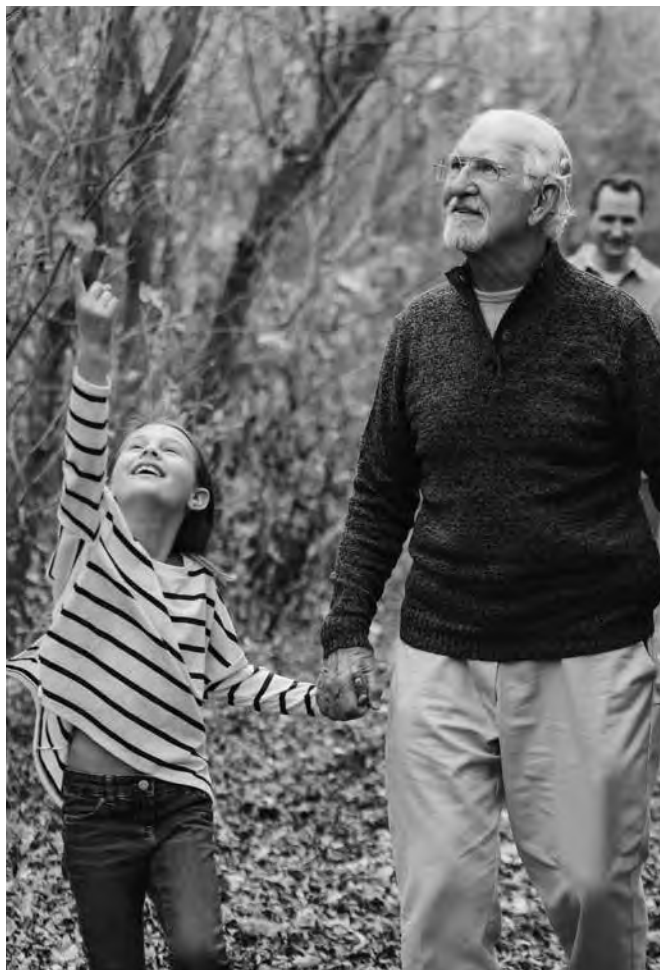
Musical activities – Music has universal appeal. Listening to a specific song may or may not be familiar to the individual, but it may be enjoyable because of its rhythmic quality and its ability to trigger emotions and memories. Musical activities might include playing songs, singing familiar songs, dancing, reminiscing about music and past events, or playing musical games like "Name That Tune." Listening to a favorite musical or opera and discussing the story and the composers can be enjoyable for both of you. Consider attending a concert or an afternoon matinee of a musical production. Such activities might also be useful for a visitor unsure about what to do or talk about during a visit. Music can also be used help soothe strong emotions.

Pets – There is something magical about the presence of a dog, cat, or bird; they seem to bring people to life. Pets can offer opportunities for a person with dementia to still enjoy some responsibilities. For example, he or she could perform basic pet care activities such as grooming, feeding, and exercising. Being with an animal also increases socialization, decreases anxiety, and provides a nice diversion from the frustration of memory loss.

Gardening – Staying connected to nature is another way to be productive and care for other living things. Working with plants indoors or in an outdoor garden can spur memories of past summer days and enjoyable times spent outside. Planting herbs, flowers, and vegetables can help support remaining talents and provide an ongoing project. Watering the plants each day, discussing their progress, and reminiscing about past gardening experiences make the days fuller and more meaningful.



"Emily spends hours every day taking her clothes out of the closet and folding them neatly on her bed. It keeps her busy and happy. Her daughter re-hangs them every evening."



Children – Staying in touch with children of all ages keeps a bridge between the generations and can often stimulate conversation and memories. Both children and older adults increase their self-esteem, develop mutual respect, and form deeper bonds if they can enjoy their time together. Consider playing simple board games or reading stories or books together. Consider visiting relatives with small children and having young mothers visit with their babies. Walks in the park and school yards provide exercise and trigger conversations about children. Consider attending school or church programs involving young people. Because of diminishing capacity, visits should be supervised.

Outings – Early in the disease, outings that were fun in the past should be continued. Consider such outings even as the disease progresses and modify them as needed. Trips can include walks at the zoo, botanical gardens, forest preserves, or shopping malls. A swimming pool during a slow time offers great sensory stimulation. You may want to consider using a business card for such public outings that states, “My companion has Alzheimer’s disease. Thanks for your consideration.” These cards are in the back of this book, but call the Helpline if you need additional cards. This information can be shared with store clerks and restaurant staff and can make outings more comfortable for all involved. Outings should be carefully planned based on length of the activity, time of day, and destination that allows for maximum success.

Physical fitness – Staying physically active is a key component of well-being. Not only does exercise provide physical benefits but it can also improve mood. A daily walking routine is 1 of the simplest and most beneficial physical activities. If the person with dementia walks alone, then an ongoing assessment of safety is critical. It is a challenge to allow the person with dementia to be independent while at the same time planning for safety. Consider making “Sit and Be Fit” a regular part of a daily routine. This is a TV program that emphasizes range of motion and low-impact aerobic exercise. There are exercise videos specifically tailored to the exercise requirements of older adults. As in any exercise program, a standard routine should be followed to ensure proper warm up and cool down. Exercise should always be followed by a drink of water or juice to ensure proper hydration. Some adult day centers provide fitness programs.

Adapting activities – All activities can be designed to meet the abilities and needs of the person with dementia. Whether the person is participating fully or is a passive observer, each activity can be adjusted to meet his or her specific needs. Regardless of the activities that are chosen to fill the day, you must take the lead and choose what will be most enjoyable for all those concerned. Whether an activity can be done alone by someone with dementia or must be carried out with others, the main point is to maximize opportunities for success and enjoyment.



Howard was a building inspector. His wife bought him a clipboard with pad and pencil. He spends part of each day "inspecting."

Exercise

Exercise aids sleep, relieves tension and restlessness, regulates appetite, helps digestion, and improves strength, coordination, and flexibility.

- Consult a medical professional if the person has medical problems that may limit the ability to exercise.
- Continue as long as possible with the person's usual exercise routine, if there is one. If there is not, attempt some type of daily exercise.

- Encourage exercises that are enjoyable and that the person can do well enough to give a feeling of satisfaction.
- Walking is easy and safe. It also provides a change of pace and a chance to get out of the house. Grocery shopping and window-shopping involve walking and provide exercise.
- Dancing is good exercise and can be fun and relaxing.
- Playing with pets and children can be a pleasurable way to get some exercise.
- Exercises can be done sitting in a chair while listening to music.
- Remember to consult a doctor before starting an exercise routine for a person with any medical problems or physical limitations.
- Ask your doctor to write a prescription for a physical therapist to come to your home to set up an exercise program for the person.
- Ask your local Visiting Nurse Association, hospital social worker, or librarian to help you find books on exercises for people with physical limitations.

Any type of movement can provide exercise:

- Sweeping the floor
- Raking leaves
- Tossing a ball
- Riding a stationary bike
- Rocking in a rocking chair

Dining Out

Planning ahead is important so that eating out can be a pleasant experience.

- Dine when restaurants are least busy.
- Avoid very noisy restaurants.
- Make reservations to avoid waiting in line.
- Sit near the restroom.
- You may want to talk with the restaurant manager about the person's illness, explain his or her need for assistance in the bathroom, and establish who is paying the bill.
- Dine with a few people rather than a large group.
- Allow the person to sit quietly if it is more comfortable than joining in the conversation.
- Spending some time talking about familiar past events will allow the person with dementia to feel that they have something worthwhile to contribute to the conversation.
- Offer two options of meals instead of an overwhelming menu.
- Use the "The person I am with has Alzheimer's" card.

"On a trip with my husband, he had to use the men's room. I permitted him to go in alone. When he did not return, I asked another man to look for him. My husband had locked himself in a broom closet. The experience was terrifying for him – as well as for myself. After that horrible experience, I would ask a man to check if anyone was using the bathroom and then to stand guard outside for me while I took him into the john."

"Taking my wife shopping was a very hard experience. We had to watch her very closely. She would put things in her pockets, thinking that she could just walk out of the store with them; that they were hers."

Shopping

Shopping can be a good activity for a person with dementia if care is taken to anticipate and avoid potential mishaps.

- Window-shopping is a form of exercise and can be a good leisure activity.
- Grocery shopping involves exercise and helps the person with dementia feel useful.
- If necessary, explain to others privately the nature of the illness.
- Shop when stores are least busy.
- Keep the person busy by giving them things to hold, asking them to push the cart, or check items off the shopping list.
- Before leaving the store, check for items in the person's pockets or plan ahead by choosing clothes without pockets.
- In a difficult situation, distract the person or move to another location to avoid embarrassment for everyone involved.

When taking patients shopping or traveling, be sure they are dressed in bright colors so that they will be easy to spot in a crowd if you should get separated.

Visiting the Doctor

It can often be difficult to get a loved one to go to the doctor for a diagnosis or even just a routine checkup. Try to restate your position by validating the person's fears. Agree with the arguments, but also state your position: "I know you are healthy, and you feel you don't need to see a doctor, but I would feel so much better knowing that you have a clean bill of health."

In many cases, the person is familiar with the symptoms of Alzheimer's and fears getting an actual diagnosis. Do not say the words "Alzheimer's" or "dementia." These words are red flags for seniors. You may try to reassure your loved one that there are some treatable conditions that cause similar symptoms to occur (new medications, hearing loss, etc).

Try not to take your loved one's disagreements personally. The following suggestions may help. Please keep in mind that the tips are given with your loved one's best interest and well-being at heart.

Getting the Person to the Doctor

Schedule the appointment at a time of day when the person feels best or rested (eg, early in the day, just after an afternoon nap). To avoid making the person nervous or worried about a doctor's visit, it is best not to give the person too much advance notice of the appointment. Tell the person the day of or before the appointment.

Have the caregiver go as a patient also. Tell the loved one you need to go to the doctor. Ask if they will come along. The caregiver could get blood pressure checked, etc, by a nurse. This may make the person feel more at ease about going. At the same time, the physician may evaluate your loved one.

Ask your loved one's physician to call to schedule an appointment. Often, the doctor's office will work with the caregiver on getting the person evaluated. The office may call and ask your loved one to schedule an appointment since he or she hasn't been in for some time. Most often, the person will schedule with the doctor's encouragement. You may want to make sure that the physician you select is experienced in diagnosing and treating dementia.

Get the doctor or pharmacist involved. The loved one may be told that an evaluation or trip to the doctor may be required to continue a current prescription. This should persuade your loved one to schedule the appointment they need.

Call ahead and explain your concerns. Many individuals in the early stages of Alzheimer's behave well in short social situations, making it difficult for a doctor to pick up on problems without some warning from the caregiver. Call ahead and give a description of your loved one's behavior.

As a last resort, if you are still struggling to get your loved one to the doctor, give yourself permission to alter the truth. One caregiver wrote a loved one a letter resembling that of the insurance company, stating that the person was due for a physical. Keep in mind that you do this for your loved one's health and well-being. The sooner the diagnosis can be made, the sooner the person can begin treatment and future legal and financial planning can occur.

Effective communication with your doctor is important when you are seeking a diagnosis. For more information, visit alz.org/alzheimers_disease_visiting_with_your_physician.asp

Preparing for the Doctor's Visit

Doctors have a limited amount of time to spend with each patient. Make the most of your visit by being prepared. Here is a checklist to help you get ready.

- Take all medications, both over-the-counter (vitamins, aspirin) and prescription, to the visit. Write them all down and take the list if that's easier.
- Make a list of past and current health problems. Note if other family members had illnesses that caused memory problems.
- Make a list of concerns. Keep a log documenting symptoms/behaviors, when they start, what time of day, and how frequently they occur. Share this information with the doctor. For example:

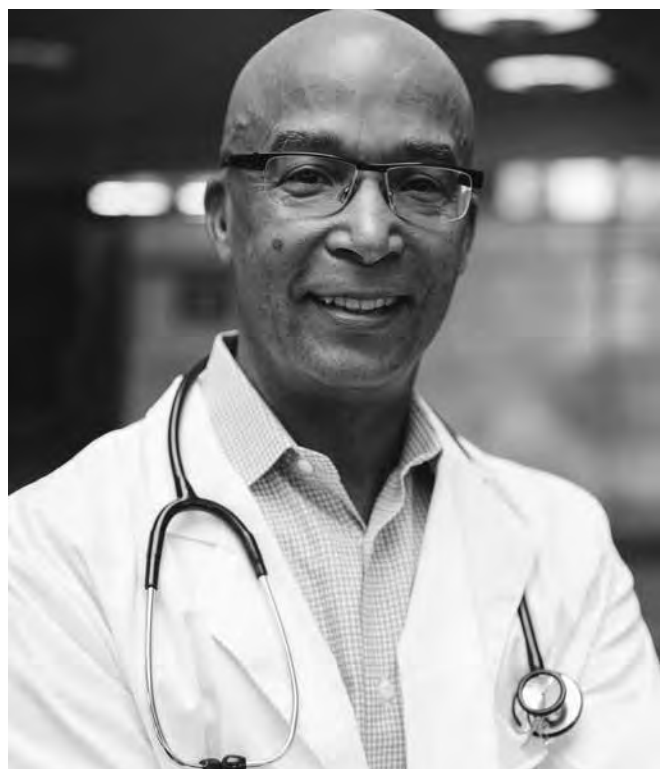
"Last Tuesday, my spouse/partner got lost on the way home from the store."

"My spouse/partner hasn't been sleeping well at night for about a month. He/she wakes up three times a night upset about something."

- Give your concerns to the doctor or nurse prior to the appointment either in writing, by fax, or e-mail or by making a phone call.
- Bring a pad of paper and a pencil to take notes during the doctor visit.
- If the person wears glasses and/or a hearing aid, be sure that he or she is wearing the glasses and/or hearing aid. Also make sure the hearing aid is working properly.

At the Doctor's Office

- Ask the doctor to explain any tests and their purposes.
- Ask the doctor to explain anything you are unclear about.
- Take notes during the visit.
- Answer the doctor's questions honestly and to the best of your ability.
- Ask the doctor any questions you need answered:
- Under what circumstances should we contact your office?
- What will our regular appointment schedule be (eg, every six months)?
- Can we schedule our next appointment now?
- If symptoms get worse over time, the doctor may need to order more tests.
- Ask if the doctor allows questions via e-mail in between office visits.



Tips for Follow-up Doctor Visits

At each visit, the doctor will assess the person's progress. You can help keep track of changes in the person's condition and share them with the doctor.

- Make a list of the types of issues and concerns you want to discuss with the doctor. Consider faxing or e-mailing the list to the doctor the day before the visit.
- Bring an updated list of the person's over-the-counter and prescription medications to each visit.
- Make notes of any changes in memory, symptoms, mood, behaviors, and/or general health. Also record when the changes first occurred, how often they happen, and when it happens.
- If you don't understand something, ask questions until you do. Don't be afraid to speak up and share your point of view. Take notes during each visit.

Visiting the Doctor in the Later Stages

In the later stages of Alzheimer's you may experience different obstacles when trying to get your loved one to see his/her physician. Obstinate behavior and acting out may make your trip difficult. Sometimes just getting your loved one out the front door may be a problem. The following suggestions may help your trip to the doctor go smoothly:

Simplify what you tell your loved one.

If the person questions where you are going, say you are going to the doctor and then out to lunch or for ice cream. This may take the emphasis off the doctor visit. Also, try to be very reassuring; this may be a frightening and strange experience for your loved one.

Take someone with you. If possible, take a third person along to help in the car while you drive as well as to assist you in occupying your loved one while you wait.

Plan the trip out well. Know where you are going. You may also call ahead and warn the nurse and/or doctor in advance about the person's behavior if you will be waiting for a long period. Bring distractions along such as snacks or favorite pictures.

Use other physical problems as an excuse. If the person has any discomforts, such as a hip hurting, explain that the doctor will give them something to help their hip.

A prescription may help calm. If the person is extremely anxious and acting out, a prescription to relax your loved one may make the trip easier for both of you.

See if the doctor will do a home visit.

It is rare today, but there are still some visiting physicians. A nurse practitioner or visiting nurse service may be able to do an assessment and report to the physician as long as your loved one's problems are not emergencies. Please call the Helpline for a list of physicians or providers that will make house calls.

When Hospitalization Is Necessary

Spending time in a hospital can be an uncomfortable and even frightening experience for anyone, but even more so for a person with Alzheimer's disease. Individuals with memory loss are completely dependent upon consistency and routine in their daily lives and may become disoriented and confused. Strange hands and faces, sterile and cold rooms, different food, unfamiliar beds and bathrooms, and what may be perceived as an inappropriate touch by unknown healthcare professionals are just a few things that can make a trip to the hospital traumatic. Add to all of the above the presence of pain, the prospect of surgery and possible effects of anesthesia, and we know that a short trip to the emergency room or a planned visit of several days or weeks is something that requires careful planning ahead.

Planning ahead can make any trip to the hospital easier for you and the individual with Alzheimer's disease. It may be helpful to keep a small bag packed with the following:

- A simple document listing the person's name, address, insurance companies (including policy numbers), Medicare and Medicaid card numbers, doctors, and prescriptions
- A list of personal telephone numbers of family, friends, and clergy
- Copies of important papers such as power of attorney, living will, appointment of healthcare representative, etc

- A change of clothes
- A card that says something like, "please understand that my companion has a memory disorder; let me help with specific questions"
- A small object that may be of comfort to the person, such as a family photo
- A sealed snack such as a pack of crackers and a bottle of water or juice in case you have to wait
- A small amount of cash

To prevent any issues, someone may need to stay with the patient for the entire hospital stay.

Handling a Visit to the Emergency Room

By preparing in advance, you can help reduce some of the stress and strain that may accompany an emergency hospital visit. After arriving at the emergency room, the following should be kept in mind:

- Be patient; it could be a long wait, and results from lab tests take time.
- Try to remain calm and offer reassurance to your loved one. They may not remember the actual event that resulted in this injury or realize they are ill.
- Remember that emergency room staff often has little if any training in Alzheimer's disease, so be a gentle educator and advocate.
- Be sure that you have any directions needed for follow-up care before you leave the emergency room.

Handling a Planned Hospital Stay

There can be many frustrations when experiencing a planned hospital stay with a loved one with Alzheimer's disease. Acute care nurses in most hospitals do not have the amount of time necessary to keep persons with Alzheimer's company and provide the needed sense of safety and security. Though caring and compassionate, many nurses may have a very limited amount of training in caring for the specific needs of individuals with Alzheimer's disease. When taking a loved one to the hospital for a planned visit that may include surgery, please keep the following in mind:

- Consider how to avoid any overnight stays. Ask your physician if the procedure could be done in the office or as an outpatient.
- If possible, consider getting a private room. Although it may be slightly more expensive, the privacy may be an advantage.

- Discuss specifics of the procedure with the physician(s) and stress your need to keep lines of communication open.
- Take an active role in your loved one's hospital care. A reminder that the person has Alzheimer's disease may be helpful at times. Ask questions about medications and pain control.
- Watch for safety issues. Make sure the person is well supervised. Try to set up a schedule with family and friends for around-the-clock companionship. This will not only be a comfort to the person but will assist the staff as well.
- Remember that a person with dementia may lose ground during a hospital stay. This may be due in part to the administering of anesthetics or narcotics, but may also be a result of the unavoidable traumatic nature of the experience. Restoring individuals to their preoperative functioning level may never occur.

When making a decision about surgery, families should first consider the wishes of the individual with Alzheimer's. Other factors may impact the decision, including the benefits of the procedure, the capacity to handle the change in routine, and the individual's stage in the disease process. The important question may be "will this improve my loved one's quality of life?"



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Communication Challenges

The way in which Alzheimer's disease affects communication will vary with each person. The person with dementia may find it increasingly difficult to express with words and have trouble understanding what has been said. Those who interact with the person may recognize some of the following changes:

- Difficulty finding the right words
- Using familiar words repeatedly
- Inventing new words to describe familiar objects
- Easily losing train of thought
- Difficulty organizing words logically
- Reverting to speaking in a native language
- Speaking less often
- Relying on nonverbal gestures more often

Keep in mind that a variety of physical conditions and medications can also affect communication. Be sure to check with a physician when you notice significant changes.

Helping the Person With Alzheimer's Disease Communicate

Communicating with a person affected by Alzheimer's disease requires patience and understanding. First and foremost, you must be a good listener. When helping the person communicate:

Be patient and supportive. Let the person know you're listening and trying to understand what he or she is saying.

Show your interest. Maintain eye contact and show interest about what is being said.

Offer comfort and reassurance. If the person is having difficulty communicating, provide reassurance. Encourage him or her to continue to explain thoughts.

Allow time for response. Let the person think about and describe what they want. Be careful not to interrupt.

Avoid criticizing or correcting. Don't tell the person what's being said is incorrect; rather, listen and try to find meaning in what is being said. Repeat what was said if clarification is needed.

Don't argue. If the person says something you don't agree with, let it be. Arguing often only makes things worse.



"When it was time to go to bed, my wife would refuse to sleep with me because she did not know who I was. I solved the problem by sitting on the bed with her for about a half hour prior to bedtime and going through old photo albums."

Offer a guess. If the person uses the wrong word or cannot find a word, try helping out. If you understand what is being said, it may not be necessary to provide the correct word. In either case, be careful not to cause unnecessary frustration.

Focus on feelings, not facts. Sometimes, the emotions being expressed are more important than what is being said. Look for the feelings behind the words. At times, tone of voice and other actions may help you understand how the person is really feeling.

Limit your distractions. Find a quiet place so you won't be interrupted.

Encourage nonverbal communication. If you don't understand what the person is trying to say, ask them to point or gesture.



"On days when I would have to take my husband out, I used to tell him of our plans the first thing in the morning. Upon telling him, he would get very anxious and follow me around the house saying, 'We are going to be late,' over and over again. Now I no longer tell him of our plans until it is time to leave. I just say, 'Let's go.' He puts on his coat and we leave."

Helping the Person With Alzheimer's Disease Understand

As Alzheimer's disease progresses, communication can become increasingly challenging. Sensitive, ongoing communication is important, no matter how difficult it may become or how confused the person may appear. Although your loved one may not always respond, they still require and benefit from continued communication.

When communicating with a person who has Alzheimer's disease, choose words carefully. To enhance your interactions, try some of the following techniques:

Identify yourself. Approach from the front and tell them who you are.

Address the person by name. This is not only courteous, but it also helps orient your loved one and get their full attention.

Use short, simple, familiar words and sentences. Don't overwhelm with lengthy requests or stories. In some cases, slang words may be helpful.

Talk slowly and clearly. Be aware of speed and clarity when speaking. Speak slowly and clearly.

Give one-step directions. Break tasks and instructions into clear, simple steps, giving one step at a time.

Ask one question at a time. Don't overwhelm or confuse with too many questions at once.

Patiently wait for a response. The person may need some extra time to process your request. Allow time to respond and offer encouragement.

Repeat information or questions. If you do not get a response, wait a moment and ask again. Use the same phrasing and words as before.

Turn questions into answers. Try providing a solution rather than asking a question. For example, you could say, "The bathroom is right here" instead of asking "do you need to use the bathroom?"

Avoid literal expressions. Directions such as "hop in!" may be taken literally and cause unnecessary confusion.

Avoid pronouns. Instead of saying "here it is," try saying "here is your hat."

Emphasize key words. Stress words that are most important, such as "here is your *coffee*."

Make negatives more positive. Instead of saying "don't go there," try saying "let's go here."

Give visual clues. Demonstrate your request by pointing, touching, or beginning the task for the person.

Avoid quizzing. Some reminiscence can be healthy, but avoid asking "do you remember when ... ?" or using statements like "you should know who that is."

Provide simple explanations. Avoid using logic and reason. Provide thorough responses in a clear and concise way.

Write things down. Try using written explanations for reminders when verbal ones seem too confusing.

Try again later. If the person is not paying attention, try to communicate again a few moments later.

Treat with respect. Avoid talking down to or as if the person isn't there.

Also, be aware of the tone you use:

- Speak slowly and distinctly.
- Use a gentle and relaxed tone of voice. A lower voice pitch is more calming.
- Convey an easy-going, nondemanding manner of speaking.
- Be aware of your feelings and attitude. They're often communicated, unintentionally, through tone of voice.

Pay special attention to your body language:

- Always approach the person from the front and avoid sudden movements
- Maintain eye contact.
- Be aware of your stance to avoid sending a negative message.
- Use positive and friendly facial expressions.
- Use nonverbals, such as pointing, gesturing, and touching.



"Sometimes she'll ask the same question over and over again. It's okay for awhile, but then it gets to me. I get frustrated and snap at her... then we both feel bad."

Repetitive Speech and Gestures

- Using a calm voice, respond to the questions with a brief, simple statement. Try using touch and direct eye contact when you respond. Your loved one may just need some extra reassurance. Try and respond to the emotional content of the statements.
- Try distracting the person with a pleasurable activity such as going for a walk, having a snack, looking through old pictures, or going for a drive. Play music or give the person a repetitive and simple task, such as separating or rolling coins, sweeping, vacuuming, folding towels, etc.
- Use a simple written message for those who can still read (eg, "Joanne will be home at 5 p.m.>").
- Do not discuss plans for activities or appointments until just prior to the event. This will help the person avoid asking about it days ahead of time.
- Try ignoring the behavior. This can make the person angry or agitated, but sometimes questions will stop if they are not reinforced by your behavior. Ignoring may be an especially good idea when the caregiver is irritated, as it keeps the patient from picking up on angry tones of voice.
- Check with your physician. Sometimes movements like rocking or tongue rolling are related to medications.

Behavior

Learn how to assess challenging behaviors. Not all behaviors are problems. If behaviors cause difficulties for the person, caregiver, or others, the best strategy may be to do nothing. If a particular behavior is a challenge, try to understand it first.

Potential Causes for Changes in Behaviors

- Changes in the brain due to the progression of the disease
- Physical discomfort due to a secondary illness or pain
- Medication side effects
- Over-stimulating or over-demanding environment
- Unfamiliar surroundings (even if only in the person's mind)
- Attempts by the person with dementia to communicate frustrations, desires, and emotions

Understanding Challenging Behaviors

All behavior has meaning and is a form of communication. People with memory loss retain their desire to control their lives. However, memory loss creates fear and uncertainty and lowers the person's threshold for stress. Often, both the person with dementia and the caregiver are in a cycle of fatigue, which magnifies challenging behaviors.

Responding to Challenging Behaviors

Inventory – is the behavior a problem? Can it cause harm to your loved one or someone else? If it's not a problem or threat, allow the behavior to continue.

Apply the AD model: A = Assure, D = Distract or Direct.

Reassess or change your plan as necessary.

Techniques for Prevention

Diversion or distraction – Shift the person's attention from one stimulus to another.

Removal – Separate the person from the situation or stimulus.

Redirection – Move or shift energy from one activity to another.

Task breakdown – Separate an activity into smaller, simpler steps.

Stimulus control – Provide limited choices.

Environmental controls – Adjust noise, lighting, and temperature.

Reassurance – Provide a sense of safety and security.

Setting limits – Take control of the situation and prevent certain actions or activities from happening.

"Margaret was afraid of the red-haired woman who kept looking in the windows. Her husband calmed her by saying that the woman had been hired to block-watch and protect the neighborhood."

Common Behaviors and Typical Meanings

Anxiety/Agitation

A general unrest, uneasiness or apprehension that may include hostile actions, such as shouting, screaming, and object throwing is usually a response to misinterpretation of environmental factors, including other people.

Problematic Wandering

A person with dementia may wander to leave an area that creates discomfort, to expend excess energy, or because of lifelong patterns established by work or routines.

This can be a minor irritation or a safety concern. Sometimes wandering can be caused by a delusion, such as the person searching for a loved one. Whatever the cause, wandering often requires careful and creative management to prevent injury.

Aggressive Reactions

Usually directed at the caregiver or another individual, hitting, pushing, or threatening are most common and occur when a caregiver attempts to help an individual. The person with Alzheimer's can cause injury to themselves or another person.

Rummaging

The person with Alzheimer's may be looking for something meaningful or comforting.

Repetitive Crying Out

This is generally a result of unresolved pain or discomfort.

Remember, this really is not about you:

- Remove yourself emotionally.
- Listen for key points.
- Restate the problem.
- Clarify the desired action.
- Stay calm.

Combative Behavior

As the disease progresses, momentary frustration can quickly develop into anxiety and fear. When this happens, it is natural for your loved one to feel threatened. This can trigger physical aggression as an irrational attempt at self-protection or to gain some control of the situation.

Types of behavior that can occur:

- Hair-pulling
- Spitting
- Kicking
- Pushing, hitting, and pounding
- Fierce arguing and shouting

Tune in on yourself and the situation:

- Stop what you are doing, step back, and take a deep breath.
- Remind yourself that this is caused by the disease.
- Do not get angry.
- Think about what your loved one is feeling.
- Reflect on your behavior: Was I pushing to get something done? Am I being impatient? Did I present too many choices?



"My husband refuses to change his clothes. He will take off his clothes to change into pajamas but will not let me touch them. My solution is to wash the clothes while he is sleeping. I remove his belt and wallet, wash and dry the clothes, and then put everything back exactly as he left them."

Steps to take when your loved one is angry:

- Check for physical discomfort (wet pants, chilly, or startled by a loud noise).
- Make eye contact and speak in a gentle voice.
- Talk in ways that are positive and reassuring.
- Help your loved one feel safe.
- Walk away for a few minutes; this often works wonders!

Take Threats to Your Physical Safety Seriously

It is important to take care of your own safety in any threatening situation. If you feel physically threatened, it is important to immediately remove yourself from the threatening situation (walk away to let things cool down, lock yourself in a bedroom, dial 911, or leave home and get help before reentering). You cannot help the person with Alzheimer's until your own personal safety is assured.

- Remove all weapons (guns, hunting knives, etc) from the house. *This should be done whether or not there is threatening behavior.*
- Have a plan for how you will deal with emergency episodes.
- Is there a neighbor, friend, or relative you can call who can come on a moment's notice?
- If you ever have to leave the house in a hurry without a key, do you have one hidden somewhere so you can get back in?

Do not hesitate to call 911 and explain that your family member has dementia.

"Last week I looked in his wallet and there was \$900. I called the bank and he'd made a \$2,000 withdrawal. I have no idea where the rest is!"

Handling Money and Valuables

- Be aware that taking care of money is important to a person's sense of independence. As much as possible, involve the person in the transition to new arrangements for handling money and bills.
- Contact creditors to determine if any problems have arisen.
- Allowing the person to keep a small amount of cash may help the person feel independent and secure.
- If the person with Alzheimer's disease claims that someone has taken his or her money, make sure that someone has not actually taken advantage of him or her.
- Avoid arguments about money problems or accusations of stealing. Do not become defensive if the person accuses you or other family or friends of taking money and other valuables. This is a normal reaction to gaps in memory and increasing confusion. Try to remember that the person is not being purposely malicious.
- Look into long-term tools for financial management such as durable powers of attorney, trusts or conservatorship, or joint bank accounts. Consult your attorney, your accountant, or a financial counselor for the best options for your individual situation.
- Remove credit cards from the person's purse or wallet.

- Keep lots of family pictures and identification cards in the person's wallet. Keep a small amount of money. Small bills may seem like more. For example, try a \$5 bill and five \$1 bills instead of a \$10 bill.
- Arrange for direct deposit of checks when possible. Watch the mail carefully for checks you are expecting.
- Locate valuables such as stock and bond certificates, wills, deeds, titles, life insurance policies, good jewelry, etc, and place them in a safety deposit box.

Notify the bank that the person is memory-impaired and that you should be notified of any large transactions before they are processed.



"I have to be sure to get to the mailbox before she does. Last month she hid two bills and we got late notices before I even knew things had come due."

Shadowing or Clinging

Following the caregiver from room to room may give the person with Alzheimer's a needed sense of security but can be difficult on family members. Shadowing, or clinging, may result from the anxiety caused by a scary or overwhelming situation, or from simply not knowing what else to do.

- Reducing confusion, noise, and clutter in the household environment may lessen the need to stay with the caregiver.
- If clinging seems to be reduced by physical contact, try substituting a pet, doll, or stuffed animal.
- Provide a useful, diverting activity while you are busy with something else. This gives the person the opportunity to feel helpful, rather than helpless and needy.
- If constant attention is needed, regular "breaks" should be scheduled for the caregiver.

Embarrassing Moments

There may be public episodes of:

- Inappropriate sexuality
- Cussing/swearing, making off-color or rude remarks
- Spitting
- Accusing people of theft, abuse, infidelity, or neglect
- Other disturbing behavior

Remember that the disease is causing this behavior. Chances are that if you criticize the afflicted person for misbehaving, confusion and distress will increase. Use finesse to guide, distract, and redirect.

Small "business card" handouts are available to you at the Alzheimer's Association office. You may want to keep some with you to hand out (see page 87 for cards you may cut apart and use).

Thank You For Your Patience

The person I am with has Alzheimer's disease, and may require a few extra moments.

Using the cards can bring different responses:

- You may get puzzled looks, but that is okay.
- Most readers of the card will smile and tell you that they understand, and perhaps that they also know someone who has Alzheimer's disease.

Inappropriate Sexual Behaviors

- The person is likely reacting to what feels good and does not remember the rules we were taught about proper social behavior.
- Remain calm, distract the person with another activity, or remove the person from the situation.
- Note the environmental circumstances of the behavior.
- A counselor may provide the caregiver with suggestions and emotional support.
- If necessary, sleep in a separate bed or bedroom.
- Consult your physician. In some cases, medication may temper sexually aggressive or violent behaviors.
- Protect yourself from any abusive behavior.
- Try to anticipate problems before they arise and seek help as needed.
- Remember, everyone has the basic human desire for touch, warmth, and intimacy.



"Lately, Mom has been trying to undress at the Day Care Center. It just started in the last two weeks. If she starts doing it when she is out with me, I don't know what I would do."

Profanity and Obscenity

The person may forget social skills or respond on impulse. As a result, the use of profanity or obscenity may escalate during times of stress. Remember that the person is not deliberately trying to upset you but is affected by a disease that compromises control over behavior and impulses.

- Try to remain calm. You can try to correct the use of profanity by gently requesting that the person refrain from using it.
- If that does not work, try to ignore it.
- Explain to those present (grandchildren, etc) that the behavior is the result of the illness, not the person.
- Distract the person with a different topic or activity, and if necessary, remove the person from the situation.



"My husband was always a polite Christian person... always considerate of others. Now he swears like a sailor. Before his illness, he'd never dream of using such words."

The Environment

Think prevention. Adapt the environment. Minimize danger.

- Use plenty of night-lights.
- Keep an eye on stove knobs or remove them.
- Hide weapons, knives, scissors, tools, or anything that could be dangerous. Use an electric razor to eliminate razor blades.
- Lock up anything poisonous.
- Put slide bolts on doors (top and bottom) and windows.
- Buy electrical outlet cover plugs.
- Hide items that are potentially dangerous (lighters, matches, car keys, etc)
- Supervise smoking.
- Buy a fire extinguisher.
- Turn the water heater down to 120°.
- Remove throw rugs and put railings on stairways.

Home safety takes many forms. For more information on providing a safer environment, visit alz.org or call the Alzheimer's Association 24/7 Helpline at **800-272-3900**.

Hot weather precautions: Always make sure your family member has enough water to drink. Many persons with Alzheimer's disease will not know they are thirsty or may drink very little. During the summer heat (and even during the rest of the year) we all need fluids in our body!

Late Afternoon Confusion ("Sundowning" or "Sundown Syndrome")

Sundowning refers to agitation and behavior problems that can escalate as the sun begins to set. The behavior can begin any time from mid-afternoon to sunset and can continue into the evening. The exact cause is not known; it may be the biological clock, the change in lighting as the sun moves in the western sky, or a metabolic phenomenon, such as low blood sugar or fatigue. It is a common symptom of Alzheimer's disease.

- Encourage a nap or quiet time with soft music after lunch if it does not interfere with sleeping at night.
- An early dinner or late-afternoon snack may help.
- Good lighting will sometimes assist in reducing confusion.
- Try to engage the person in a physical activity or simple chore before the anxious behavior begins.
- Decrease your expectations of the person during this time of the day.
- Reduce noise and activity level.
- It may be helpful to orient the person. Discuss the time, the place, and what is going on.
- Reassure the person.
- Schedule daily routines that require cooperation, such as baths and medication, at another time of day.
- Redirect. For example, a person who insists on "going home" to prepare dinner will respond more positively if asked what is being planned for dinner, rather than being told that he or she is already home.
- If the person appears to be increasingly anxious, a "therapeutic fib" may be in order. For example, the person may become increasingly anxious looking for a deceased loved one. You can say that you have not seen that person yet, but when you do, you'll take the loved one to the person. This response demonstrates a concern and provides reassurance and a sense of relief.
- Encourage repetitive activities such as peeling potatoes, washing tabletops, or raking leaves. Such activities can redirect frustration and offer a "failure-free" alternative.



Making Errors in Perception

Perception errors are the result of the disease. They can be visual, spatial, and/or auditory.

The person with Alzheimer's disease may:

- Walk into walls
- Have difficulty maneuvering into chairs
- Refuse to walk on dark or light floors, perhaps seeing them as holes
- Think a TV program is real
- Not realize the car is moving and open the door
- Become frightened at a reflection in a mirror
- Become confused by shadows or glare
- Think radio voices are strangers in the house
- See windows as doorways

Some adjustments can be made to the environment:

- Lock car doors.
- Cover or remove mirrors.
- Select harmless TV programs.
- Place furniture in front of windows.
- Provide good lighting.

Losing and Hiding Things

A person with dementia may not remember where to find an item or where it was last placed.

- Drawers and cabinets with everyday articles can be labeled with large printed signs. Use pictures of objects rather than written words.
- Limit the number of hiding places by locking rooms, closets, and drawers that are not regularly used.
- If necessary, important or valuable items can be kept out of sight or locked up.
- Keep track of keys, eyeglasses, hearing aids and batteries, dentures, medications, and other essential items. Keep spares whenever practical.
- Learn the person's hiding places. Try to recall old favorite hiding places for gifts, etc.
- Check trash baskets before you empty them.
- If the person with dementia insists on searching for missing items, the anxiety may have more to do with a general sense that something is missing or lacking (one's memory) than with a need to find a specific item. Reassurance or distraction may help.

"My mother has never been wrong. When she could not find her watch, beads, etc., she would always say that they had been stolen. Once in a while they would be 'returned' by the thief."

Having Delusions or Hallucinations

A delusion is a fixed, false idea. A hallucination involves seeing or hearing something that is not there. A person may become frightened, annoyed, or amused by delusions or hallucinations.

Never tell the person that he or she is crazy, stupid, or imagining things.

- You may need to enlist a friend to play the role of an authority figure (repairman, detective, etc) to whom the person with Alzheimer's will listen.
- Sometimes, a pretend phone call to "the authorities" works.
- Your doctor can be consulted if the episodes are overwhelming.
- Don't argue about the delusion or hallucination.



Wandering

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."

- A person may wander by foot but also by car, bus, or other modes of transportation.
- It can happen anytime or anyplace.
- It can be life threatening for the individual.

What the person may be looking for:

- Childhood home
- Workplace
- Mom, Dad, or children
- Favorite fishing hole

From whom or what the person may be running:

- A former mate
- Enemy soldiers
- Angry parents
- A frightening noise

What you can do to minimize danger:

- Make sure the person carries some form of identification that includes his or her name, address, phone number, and pertinent medical information. Ideally, the person should wear a Medic Alert® + Safe Return® bracelet.
- Keep a clear, recent photo on hand to help police and neighbors with identification should the person become lost. If possible, keep a photo in your cell phone.
- Change your door latch or lock. Often people with Alzheimer's disease are unable to learn how to use a new lock. You may also consider placing alarms and bells on outside doors.
- Leave a nightlight on in the hall and bathroom to prevent getting lost at night. If the person does lose his or her way during the night, gently redirect him or her back to bed.
- Remove knives, matches, scissors, etc, that could cause injury. Some caregivers may find it necessary to lock doors to the kitchen, basement, or other potentially dangerous areas.
- Put a stop sign on the inside of doors that lead to the outside or camouflage them with a curtain or screen.
- Place a black mat in front of exit doors.
- Use doorknob covers.

- Be sure the person gets exercise daily. This should help reduce excess energy and encourage restful sleep.
- Visit alzstore.com for a list of safety products available.

Call the Helpline at 800-272-3900 to inquire about registering your loved one in our Medic Alert® + Safe Return® program.

Practical suggestions for the person who wants to go home:

- Take the person for a walk or a drive.
- Keep coats, jackets, and suitcases out of sight.
- Get the person involved in an activity or divert with food, exercise, or music.
- Maintain a routine. Keep the environment as familiar, calm, and as predictable as possible.
- Have the person perform a regular, productive chore, like folding towels or setting the table.
- Ask a family member to call at a regular time or have the person call a member of the family.
- Sometimes, having a member of the family write a note with a reassuring message helps.
- Remember that home may represent a sense of security, so give the person lots of hugs and reassurance.

"Lately, she has started just taking off – she thinks she has to be going somewhere all the time. I'm afraid she'll go out of the house when my back is turned and get hurt."

Wanting to Drive the Car

One of the more emotionally challenging losses to the person with Alzheimer's is not being able to drive anymore. This is an issue that is often addressed in support groups.

The driving skills of the person with dementia need to be evaluated by the Bureau of Motor Vehicles. As difficult as it may be, the family also needs to take responsibility and evaluate the safety of the diagnosed driver. This is one of the disabling conditions that, at some point, requires a designated driver or other mode of transportation.

You can prevent the person from driving in a variety of ways:

- Hide the car keys.
- Have the ignition re-keyed.
- Have the ignition put on a hidden switch (shop around; prices vary greatly).
- Remove the distributor cap or battery connection.
- Remove or sell the car.
- Ask the doctor to write a "no driving" prescription.
- Write an official-looking letter requiring a driving test in order for driving privileges to continue.
- Contact the Indiana Bureau of Motor Vehicles.

Some things to consider if you're not certain that it's time to take away the keys:

- Does your auto insurance cover a driver with Alzheimer's?
- Have you evaluated the person's driving recently by riding along as a passenger?
- Would you feel comfortable letting the person drive the grandchildren around?
- Will the person complete a driving evaluation with an occupational therapist?
- **If your answer is "no"... IT'S TIME!**

For more information, call the Alzheimer's Association Helpline at **800-272-3900** or visit alz.org/care/alzheimers-dementia-safety.asp



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SECTION 6:

COMMUNITY RESOURCES

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Building a Community of Support

Building a community of support around yourself and the person with Alzheimer's disease will help make the journey much easier. Plan ahead so that you are ready when issues arise. As the person progresses through the disease, you will need different resources. The following table shows examples of what will be needed in each of the stages.

Stages of Caregiving	Primary Caregiver Needs	Community Resources
Stage 1 & 2	Diagnosis Information Planning	Diagnostic Center or Physician Alzheimer's Association Elder Law Attorney
Stage 3 & 4	Information Support	Alzheimer's Association Area Legal Services Support Groups Driving Assessment Safe Return
Stage 4, 5 & 6	All services above and: Respite Care Financial Assistance Care Management Possible Placement	Adult Day Services In-home Care Area Agencies on Aging Alzheimer's Association Residential Care Facility
Stage 7	All services above and assistance with care decisions	Hospice

In-Home Services

Finding and keeping a qualified home healthcare worker is a challenge and requires a plan. A licensed, bonded agency can provide caregivers who have been screened by the agency. Many families who cannot afford the agencies' fees prefer to find an independent caregiver. With either option, begin by determining the needs of the person with Alzheimer's disease. Most agencies and individual caregivers will provide services to suit your schedule, whether you require just a few hours or 24 hours a day. Support groups can be helpful in providing information on how to overcome some of the barriers to getting caregiving assistance. Below are examples

of typical needs. Of course, your needs may vary or may change over time. Be sure to inform the agency or the individual caregiver of your needs and the diagnosis.

Companionship – Provide a list of activities that the person enjoys or favorite topics of conversation.

Meal preparation – Provide a list of favorite foods. You may want to develop a meal plan that provides for adequate nutrition and hydration. It will help avoid repetition and make shopping easier.

Medications management – Provide a simple checklist of medications, dosages, and times to give them. A checklist will also reassure you that meds have been given.

Exercise – Detail the specific activities that are part of your loved one's physical therapy.

Bath and shampoo – Specify frequency and provide helpful hints.

Dressing assistance – Provide specifics on what type of help is needed. What can the person do independently?

Transportation – List any required escorted visits to the doctor, therapist, or other location.

Household chores – Light housekeeping, laundry, and grocery shopping may be handled by a home health aide.

Daily chores – Indicate chores you want completed, such as preparing food, cleaning up after meals, making the bed, and answering the door or telephone.



Adult Day Care Services

Adult day care provides social activities for the elderly. It allows older people to stay in their homes and communities longer, deterring premature or total institutionalization. Adult day care improves and maintains the physical, social, emotional, mental, and medical levels of functioning, increasing independence in the life of the older person.

Support for Families

- It is an organized service that can share in the complex burden of daily care.
- It provides psychological support in the knowledge that the older family member is involved in a social-health environment.
- It provides means by which the family is able to fulfill the desire to keep their loved one at home as long as possible.
- It allows family more time to pursue employment or leisure activities.
- It may help reduce tension within the family.
- Some centers offer bathing, skilled nursing, and/or transportation.

Community Resource Finder

Get easy access to a comprehensive listing of Alzheimer's and dementia resources, community programs and services, including in-home services and adult day services. Visit communityresourcefinder.org to start your online search.

Benefits to the Person With Dementia

- It provides structured, scheduled programs to allow for social, emotional, educational, recreational, and physical stimulation. Regular activities may include educational films, singing, discussion groups, field trips, arts and crafts, bingo, etc.
- It assists in the implementation of preventative, maintenance, or supervisory plans of care.
- It improves the quality of life and allows for extended independence.
- Services are structured to meet individual needs.

Adult day care is successful because:

- The day care center emphasizes function and not diagnosis. It stimulates the capacities for independence while providing supports for functional limitations.
- It gives seniors a purpose, which they might not otherwise establish for themselves.
- There is constant exposure to new people, interests, and surroundings.
- It might reinforce an established routine. For example, a person with dementia who previously worked outside the home is already accustomed to spending the day in a setting different from home and returning to the familiar surroundings of home in the evening.

What are the important issues?

- Safety
- Time and Energy
- Personal Hygiene
- Financial Concerns
- Behavioral Concerns
- Caregiver Issues
- Nutrition
- In-home Options

Long-term Residential Care

When or if the time comes for a person with Alzheimer's disease to move into a residential care setting (group home, assisted living, nursing home, etc), it can be very difficult for both the person and the family. In addition, finding the right residential care setting to meet the needs of the person with dementia can be challenging and time-consuming. There are several options:

Housing only – Retirement housing and senior apartments provide a place for individuals to live. Usually, each resident will have an apartment or room that includes cooking facilities. Common areas for socialization are provided, but there are no staff-planned activities. Usually no medical assistance is provided except in emergencies.

Room, board, and minimal assistance

Assisted living, board and care, group homes, community-based residential facilities, or foster home settings provide a room, one to three meals daily, a 24-hour staff, some skill in dealing with dementia, and structured activities. Levels of medical care vary greatly.

Skilled nursing services provide 24-hour care – Skilled nursing facilities, nursing homes, health and rehabilitation centers, or healthcare centers offer room and board with 24-hour staff. Some have dementia units. All meals are provided and monitored by a nutritionist. Skilled nursing and structured activities are also provided.

Ideally, planning for a move into a residential care setting should begin before admission is needed. This allows time to learn about the types of residential care available and determine which will be able to best meet your needs.

When Is the Right Time for Facility Care?

It is difficult to know when to begin looking for facility care for a loved one. However, if you are the primary caregiver for someone with Alzheimer's disease, you may begin asking this question as the disease progresses. The most important thing to remember is that there is no right time for everyone. Each person and family is different, and there are several factors to consider. To discuss these factors, a family meeting is recommended. Include family, close friends, and neighbors and, when possible, the person with Alzheimer's.

Nursing Homes: Asking the Right Questions

Sometimes the need for a nursing home comes suddenly or unexpectedly. Often, it comes when your loved one is in the hospital with a serious medical condition or injury. Choosing a home can be very difficult. Early planning and visiting can make this process easier.

You are the best judge of how many nursing homes you can visit, but try to see at least three so you can make comparisons. If possible, ask the loved one who will be living in the nursing home and other family members to visit the nursing homes with you.

Your visit will give you the chance to view provided care firsthand, talk to staff, residents, and other families, taste the food, and observe activities. It is always best to visit a facility at least twice. Make one of the visits unscheduled, during the weekend or evening, when staffing problems will be most obvious.

Talk with the nursing staff about the kind of care your loved one needs and make sure the facility can provide it:

- Is transportation available so the resident can visit his or her own doctor?
- Is physical therapy available for as long as the resident needs it?
- Does the staff have special training in dealing with dementia?
- Are there special units, programs, or services for special needs such as Alzheimer's?

One thing to consider when choosing a nursing home is location. Try to find one that family and friends can visit often.

People in nursing homes who have regular visitors usually get better care. Use your visits to observe carefully, and do not discount your personal feelings. The Nursing Home Checklist can help you compare the different facilities you visit; call the Helpline and ask for your copy.

Alzheimer's Association Services

The Alzheimer's Association 24/7 Helpline provides information, assistance, counseling and support. A Helpline specialist is always available to answer your questions and provide:

- Information and referral services
- Empathetic listening and support
- Translation of 170 languages
- Lists of agencies and community resources
- Expert advice on caregiving
- Access to additional services

Education

The Alzheimer's Association offers a variety of educational programs targeted to specific audiences: individuals with the disease and their caregivers for each stage of the disease. These programs include "Living With Alzheimer's" for those in the early, middle, and late stage of the disease. Programs are provided in-person and online. In addition, the Association offers education to healthcare and social services professionals and the community-at-large, as well as customized speaking engagements upon request.

Family and professional programs are designed to provide the necessary tools for effectively managing the care of someone with Alzheimer's disease or another dementia. Community programs are designed to heighten awareness and provide general information about Alzheimer's disease and the services of the Alzheimer's Association.

For more information about education programs, visit alz.org/indiana or call the Helpline at **800-272-3900**. You can also view recorded webinars of education programs at **training.alz.org**.

Support Groups

Support groups throughout greater Indiana meet monthly to provide caregivers and individuals with early-stage Alzheimer's an opportunity to share their expectations and receive support from others coping with the disease.

ALZConnected®

Alzconnected.org is a free online community for everyone affected by Alzheimer's or another dementia, including people with the disease, caregivers, family members, friends and individuals who have lost someone to Alzheimer's.

Care Consultation

This service is available if you need help developing a plan of care for your loved one. Appropriate resources are identified, and strategies are developed with family input. A licensed social worker is available to facilitate this process when decision making is challenged by caregiver stress, health, or family disagreement. Call 800-272-3900 to schedule an appointment.

Alzheimer's Navigator®

Visit alzheimersnavigator.org for an online assessment program to help caregivers and people with dementia evaluate their needs, execute action steps and connect with local programs and services.

Early-Stage Programs

Programs are available for individuals in the early stage of Alzheimer's disease or another dementia. The programs offer social support, answers to questions about the disease and advice about planning ahead.

I Have Alzheimer's Web Portal

If you have been diagnosed with Alzheimer's or another dementia, you are not alone. Visit alz.org/i-have-alz for a series of webpages designed with you in mind. Learn what to expect, how to plan ahead and where to find support.

Alzheimer's Association TrialMatch®

This is a free service that makes it easy for people with Alzheimer's, caregivers, and physicians to locate clinical trials based on personal criteria and location. Both healthy volunteers and individuals with the disease are needed for clinical trials. Visit alz.org/trialmatch to browse studies and sign up.

Medic-Alert® + Alzheimer's Association Safe Return®

This is a 24-hour, nationwide emergency response service for individuals with Alzheimer's or a related dementia who wander or have a medical emergency.

Community Resource Finder

Get easy access to a comprehensive listing of Alzheimer's and dementia resources, community programs and services via the Alzheimer's Association online directory at communityresourcefinder.org.

Advocacy

Advocates are volunteers that work locally and nationally to ensure that the needs of those affected by Alzheimer's disease are represented appropriately in all levels of government. More information can be found at alzimpact.org.

Resource Library

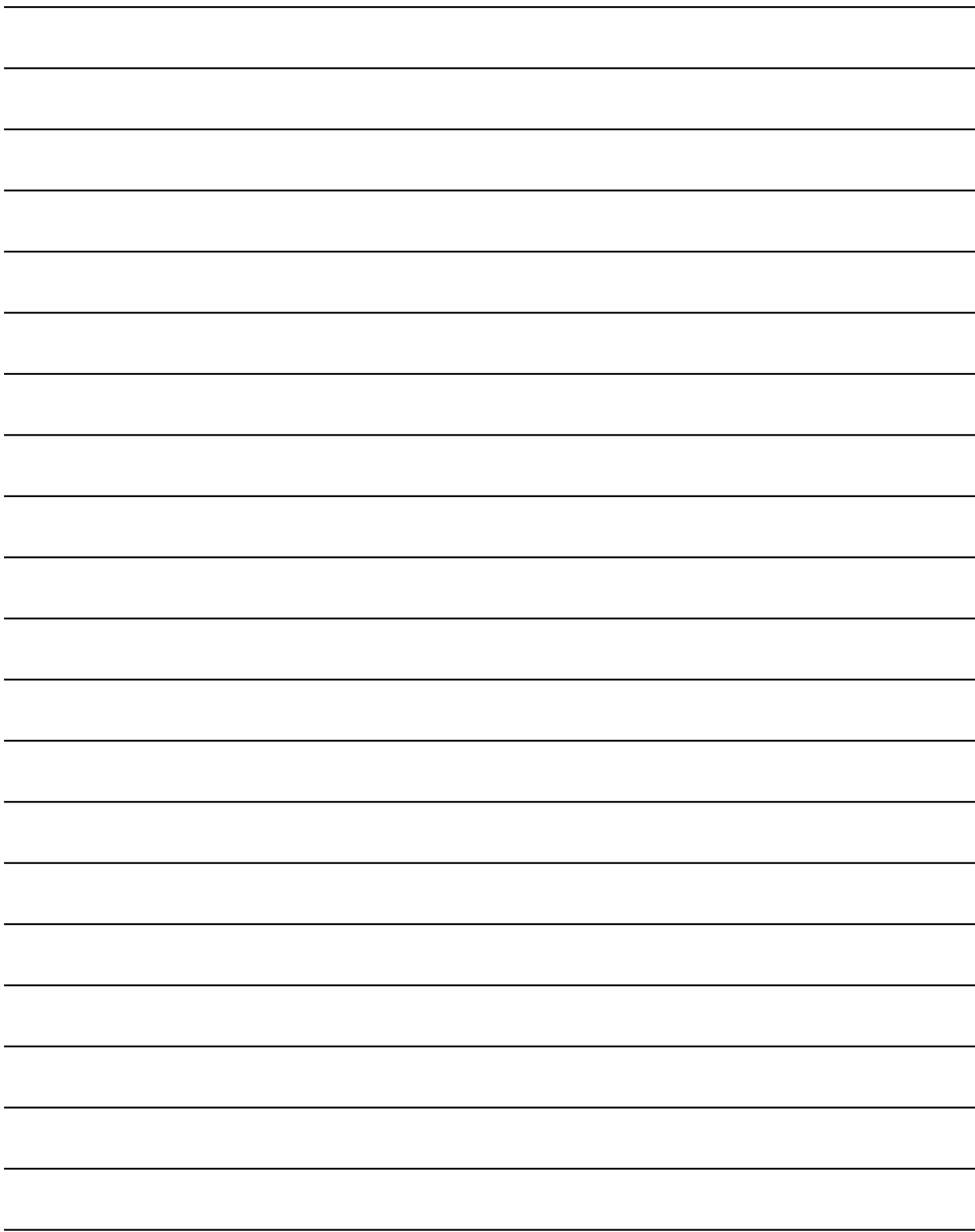
The Alzheimer Association's Benjamin B. Green-Field Library is an excellent resource center. Numerous books, articles and videos are available for use. Please contact the Alzheimer's Association for listings and availability (alz.org).

Website

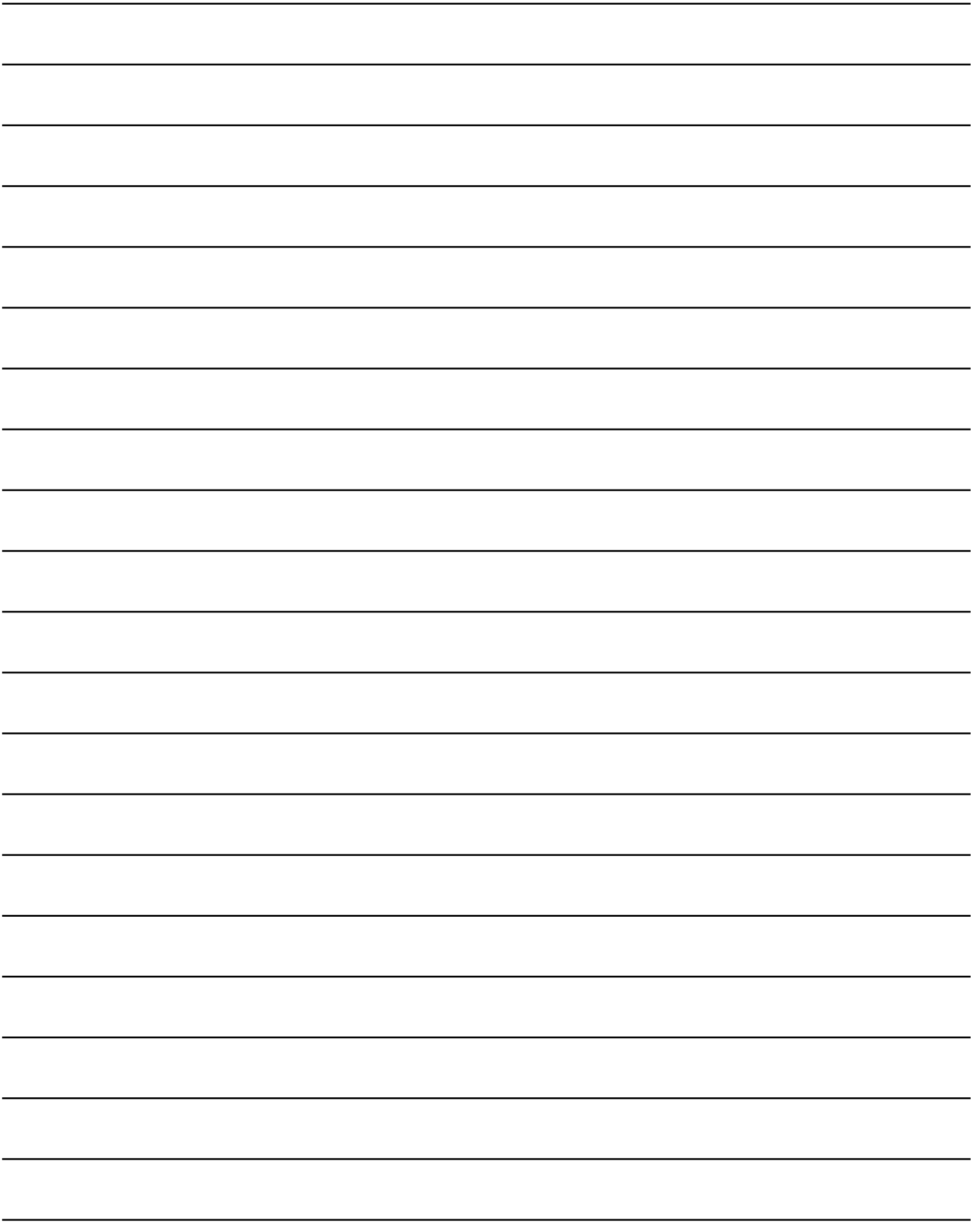
Visit the Alzheimer's Association website at alz.org/indiana for information about programs, services, support, and general information about Alzheimer's disease and other dementias.

For comprehensive tips, tricks and frequently asked questions on a variety of caregiver topics, visit alz.org/care.





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alz.org

Access reliable information and resources, such as:

- Alzheimer's Navigator® - Assess your needs and create customized action plans.
- Community Resource Finder - Find local resources online.
- ALZConnected® - Connect with other caregivers or people with dementia.
- Alzheimer's and Dementia Caregiver Center - Get information for all stages of the disease.
- Safety Center - Access information and tools.



alz.org/education

Free online workshops, including *Living with Alzheimer's: For Caregivers*



alz.org/findus

We're in communities across the country.



800.272.3900

24/7 Helpline - Available all day, every day. (TTY: 866.403.3073)

alzheimer's  association®

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support and research. Our mission is to eliminate Alzheimer's disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

Our vision is a world without Alzheimer's disease®.

800.272.3900 | alz.org/indiana