

# LEGAL GUIDES

by Middle Alabama Area Agency on Aging



ASSISTING  
ALL AGES AT  
ALL STAGES



WHAT TO DO WHEN  
A LOVED ONE  
DIES



DESIGNING A LONG-TERM  
CARE PLAN



AUTHORITY ISSUES  
FOR CAREGIVERS



**DEMENTIA FRIENDLY  
PROFESSIONALS & CAREGIVERS**

This book was created in partnership with the

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**DISCLAIMER:**

Information provided here is current through 2017. There are yearly changes to income and resource eligibility for most programs as well as copayments for Medicare and income protections for Medicaid spousal impoverishment. Substantive changes may occur in tax, VA and probate law requiring you to obtain updated information before relying on specific information provided here.

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**D**ementia is a growing concern in communities across America. The number of persons who have dementia is hard to accurately estimate since there are multiple types of dementia without accessible statistics. The Institute for Dementia Research & Prevention estimates that 70 percent of dementia cases in America is Alzheimer's, and The Alzheimer's Association estimates that the number of people living with just that disease will grow from 5.5 million today to 16 million by 2050. In addition to striking one in ten persons age 65 and older, an estimated 200,000 persons have early onset Alzheimer's with which they were diagnosed prior to age 65. Alzheimer's Disease is the 6th leading cause of death in the United States, and one in three seniors die with Alzheimer's or some other type of dementia.

Dementia is a problem of national significance, and in individual homes it is devastating. In 2016 15.9 million family members and friends provided 18.2 billion hours of unpaid assistance to those with dementia. Amazingly, 34 percent of caregivers are themselves age 65 or older.

Often cognitive decline accompanies other physical decline with medical and care planning needs, but that is not always the case. Either way, caregiving has taken on a dimension that is confusing and frustrating as affordable resources needed to meet the needs of clients/patients/loved-ones with dementia are in such limited supply, and information to meet those challenges head on can be difficult to obtain.

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**“Dementia friendly is a preparatory attitude with sleeves rolled up to work toward observable goals of improving the lives of people living with dementia.”**

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Dementia friendly is much more than sympathetic or empathetic behavior, kind nods and smiles while looking the other way. Dementia friendly is a preparatory attitude with sleeves rolled up to work toward observable goals of improving the lives of people living with dementia. In order to more effectively support and serve those persons living with dementia it is critical that caregivers - lay and professional - recognize and understand the process of cognitive decline, how to spot and prepare for it, becoming aware of daily caregiver challenges, and rise to meet those challenges with knowledgeable, sensitive and responsive services.





It is true that knowledge is power, and in the arena of caregiving for individuals with diminishing capacity, obtaining information to help maximize the caregiver's ability to cope and the care recipient's independence and quality of life is critical. In life we plan for so many things, but let's be honest, we do not often plan for disability and certainly not for loss of cognitive ability. Caregiving is often so overwhelming precisely because we are not prepared, and, frankly, even with preparation, caregiving for loved ones and clients with capacity issues has its own set of unanticipated challenges. Grief alone is crippling. Not knowing how to get help leaves everyone involved feeling hopeless and powerless. Caregiver despair is genuine.

This booklet is being provided to help bridge the gap between a lack of preparation and becoming students of dementia who obtain information to understand the scope of the issue faced by caregivers and care recipients. It is hopeful that with more information we can grow into more dementia friendly professionals who can provide the support needed by persons and families dealing with dementia issues.

So what is dementia friendly? How do we reach that state? At a minimum dementia friendly requires us to be:

## **Dementia Knowledgeable**

We will know what dementia is and what it is not. We will recognize that not all dementia is the same condition, and, certainly, not all dementia clients / patients / loved-ones are the same. Each dementia patient brings his or her personality to the condition, and it can be difficult to determine whether certain behaviors are part of dementia or elements of personality. We will know how to spot behaviors that may indicate the beginnings of dementia to allow for a quick uptake in treatment and preparatory planning. We will recognize that dementia is not on or off, rather a fluid range of cognitive functioning that might render a person sound for one activity and incapable of another without risking damage.

## **Dementia Sensitive**

We will know that there are signs of dementia yet know that not all bad judgment is dementia. We will identify and evaluate these cognitive declines which require medical intervention. We will learn appropriate responses to persons who are experiencing dementia. Regardless of legal authority to make decisions, we will seek ways to keep the person experiencing dementia in the conversation to the greatest extent possible. We will be able to assess cognitive decline, and have the tools to determine what we can and cannot do for a person asking for our help. We will recognize the spectrum nature of dementia.

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“Regardless of legal authority to make decisions, we will seek ways to keep the person experiencing dementia in the conversation to the greatest extent possible.”

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## **Dementia Responsive**

We will know where resources are, and examine what we can do in our individual disciplines and what is required of us. We will know from whom we should take instructions. We will know who is the driver of our service. We will know if we are mandatory reporters when a person is in danger, and we will give dementia patients and those who care for them priority. We will recognize their desperation and the extent of their needs. Even without ways to solve all problems now, we will respond appropriately, and we will recognize the difference in human response and legal response.



# Dementia Knowledgeable



**D**EMENTIA KNOWLEDGEABLE means understanding the scope of dementia.

There are many types of dementia, many causes of cognitive decline and multiple classification systems used to categorize the different ways dementia can present. Early diagnosis is critical to appropriate treatment. Although there are multiple causes of dementia and different presentations, they all present as a deficit in cognitive functioning.

## **What the dementias have in common**

According to Erica Wood, Esq., Commission on Law and Aging, American Bar Association and Jane Tilly, DrPH, Office of Supportive and Caregiver Services, Administration for Community Living/Administration on Aging dementia is brain disease resulting in:

- progressive decline in cognition and/or behavior from a prior level of functioning;
- decline in two or more: memory, reasoning, language, visual perceptual processes, executive functions, social interpersonal behaviors, personality;
- interference with customary activities and social relationships, causing dependence and/or alienation.

Similarly, according to the National Institute of Health (NIH) a person is considered to have dementia if he or she:

- demonstrates impairment in two or more core mental functions including memory, language skills, visual perception, ability to focus and pay attention, engage in cognitive skills such as ability to reason and solve problems.
- has a loss of brain function severe enough to prevent engaging in normal, everyday tasks.

The person with dementia may also be unable to control his or her emotions, experience personality changes and have delusions and hallucinations.



### **The Fluid Nature of Dementia**

With multiple potential limitations being the behavioral evidence of dementia, it is readily apparent that dementia can be hard to spot, and symptoms may come and go, intensify and ease off. It is critical to recognize that a person may have the capacity to do one thing while being too impaired to do another. In subsequent publications we will examine the different legal standards required for a person with cognitive deficits to engage in particular activities. For now it is important to recognize that dementia is not all or nothing, rather it exists somewhat on a spectrum and may vary day to day with the goal being to slow or prevent further decline.



As far as the numerous identifiable/diagnosable types of dementia it can best be said that dementia is a huge tent. There are many types, and some respond to treatment, and others do not.

The NIH explains that there are neurodegenerative disorders - such as Alzheimer's Disease, frontotemporal disorders and Lewy body dementia - that are progressive with irreversible loss of brain function. There is no cure. But other types of dementia can be halted or even reversed with treatment. Dementias and dementia-like symptoms respond to treatment when caused by normal pressure hydrocephalus, cerebral vasculitis, infectious disorders, drug reactions, vitamin deficiencies, alcohol abuse, depression, and brain tumors.

Though Alzheimer's Disease is the most common form of dementia, not all dementia is Alzheimer's Disease. The NIH estimates that as many as five million Americans over age 65 have Alzheimer's Disease, an estimated 20-40 percent of people with dementia have a different form of dementia, and many people actually have mixed types of dementia involving more than one form of disease. Understanding the broad range of dementias is critical in recognizing the importance of proper diagnosis and treatment.

The NIH classifies types of dementia as:

- Tauopathies in which a protein called tau clumps inside nerve cells in the brain (includes Alzheimer's Disease, corticobasal degeneration, frontotemporal disorders, progressive supranuclear palsy, argyrophilic grain disease).
- Synucleinopathies in which a protein called alpha-synuclein accumulates inside neurons (includes Dementia with Lewy bodies, Parkinson's disease dementia).
- Vascular
- Mixed

Similar categories provided by Erica Wood and Jane Tilly are:

1.) Dementia of the Alzheimer Type with initial symptoms most often including short term memory loss, forgetting conversations, repetitive comments/questions, reduced motivation and later symptoms including word-finding difficulty, visual perception disorders and reasoning problems.

2.) Dementia of the Frontotemporal Lobar Degeneration Type (2 forms):

- a.) Primary Progressive Aphasia (loss of ability to understand or express speech) with early symptoms including word-finding deficits and later symptoms including reading, spelling errors, behavioral changes and short term memory loss;



b.) Behavioral Variant Frontotemporal Dementia with early symptoms of personality change, poor judgment, inappropriate emotions, odd food habits and later symptoms of memory loss, possible motor symptoms (tremors, etc.).

3.) Lewy Body Dementia with visuospatial deficits, visual hallucinations (usually pleasant, non-threatening), fluctuating symptoms and motor symptoms (Parkinson-like).

4.) Vascular Dementia with many types of symptoms including aphasia (loss of ability to understand or express speech), behavioral changes, reduced executive functions (short term memory, reasoning and logic, decision making skills), motor symptoms with all changes dependent on brain location of stroke.

Related to chronic cardio and cerebrovascular risk factors (heart disease, hypertension, high cholesterol); progressive loss of function due to multiple successive cerebrovascular events (mini-strokes).

### **The Dementia-like Non-dementias**

There is hope for some types of cognitive decline. According to AARP, several conditions look like dementia, but technically are not. These conditions include:

1. Normal Pressure Hydrocephalus (NPH) which is a build up of spinal fluid in the brain resulting in swelling and pressure that can damage brain tissue over time. With NPH, the symptom that's usually noticed first is a distinctive gait problem, and other clues include problems with thinking and memory, a lack of concentration, and urinary incontinence or a frequent need to urinate. A neurologist can diagnose with a CT scan, MRI or spinal tap, and a shunt surgically inserted into the brain can drain fluid and can correct the situation.

2. Medication is metabolized and eliminated less efficiently as we age, and some drugs can build up and cause memory problems and other side effects that look similar to Alzheimer's disease and other permanent dementias. These offending drugs include, but are not limited to, narcotic painkillers (opiates), benzodiazepines used for sleep and anxiety, steroids and muscle relaxants. The American Geriatrics Society publishes the Beers Criteria, a list of drugs that should be used with caution, or not at all, by older people. To refer to the Beers Criteria go to the following address:

<http://www.americangeriatrics.org/files/documents/beers/2012AGSBeersCriteriaCitations.pdf>.



3. Depression can look like dementia. According to Marc Agronin, a geriatric psychiatrist in Miami and author of the 2015 book *The Dementia Caregiver*, severe depression can sometimes cause a syndrome of cognitive impairment known as pseudodementia. With treatment the cognitive impairment improves, but individuals who present with pseudodementia are at greater risk of actually developing dementia in the following few years.
4. Urinary tract infections (UTI) are a build up of bacteria in the bladder. In younger people typical symptoms include high fever and pain, but seniors rarely have those typical symptoms and UTIs go unidentified and untreated. When this happens there may be sudden memory problems, confusion, delirium, dizziness, agitation or even hallucinations, and these problems subside with antibiotics, fluids, a healthy diet and rest. Nonetheless it is important to note that UTI-induced confusion is most likely to occur in people who already have dementia and that healthy people rarely have this reaction.
5. Someone showing signs of dementia may have a benign tumor called a meningioma, which can press on certain parts of the brain and cause cognitive dysfunction.
6. A subdural hematoma, usually caused by a head injury, can result in blood collection and pressure in the brain accompanied by dementia-like symptoms.
7. Alcohol abuse, even binge drinking, can kill brain cells in areas critical for memory, thinking, decision-making and balance.

### **According to *The Alzheimer's Action Plan*:**

“Nearly one in five people over the age of sixty has some degree of hypothyroidism, meaning a sluggish thyroid.

The symptoms include forgetfulness, weight gain, depression, dry skin, intolerance to cold, muscle aches, and fatigue.

People who are hypothyroid feel as though they have mild Alzheimer's and depression all mixed into one bad day.”

### **Hospital Dementia Known as Delirium**

Harvard Health Publications reports that several major studies show that about half of people over 65 have episodes of delirium — a sudden change in mental status — during hospital stays, and those who do are at increased risk for falling, requiring nursing home care, and developing cognitive impairment and dementia.

Dr. Sharon Inouye, professor of medicine at Harvard Medical School, and colleagues developed the **Hospital Elder Life Program (HELP)** which was available at 200 hospitals in the United States as of 2016. HELP identifies patients at risk for delirium upon admission to the hospital and assigns them to receive special care to minimize six major risk factors associated with delirium — cognitive impairment, sleep deprivation, immobility, visual impairment, hearing impairment, and dehydration. Studies have found that the HELP is associated with significant reductions in the percentage of patients who develop delirium. It also helps prevent falls in the hospital, shorten hospital stays, lessen nursing home admissions and result in a lower rate of cognitive and physical decline.

In the absence of HELP in a hospital where you or your loved one is admitted, Harvard recommends that you do the following when a hospital admission is necessary:

- **Gather your records.** Prepare a “medical information sheet” listing all your allergies, the names and phone numbers of your physicians and your usual pharmacy, all your medical conditions, and all the medications — both prescription and nonprescription — you’re currently taking. Have your medical records forwarded to the doctors who will be caring for you.
- **Bring the essentials.** You’ll need your glasses, hearing aids and fresh batteries, and dentures. Ask if you can bring a few familiar things like family photos, a good book, or an MP3 player with your favorite music or relaxation exercises.
- **Set up a support team.** Let family and friends know you’re being hospitalized and ask them to visit.

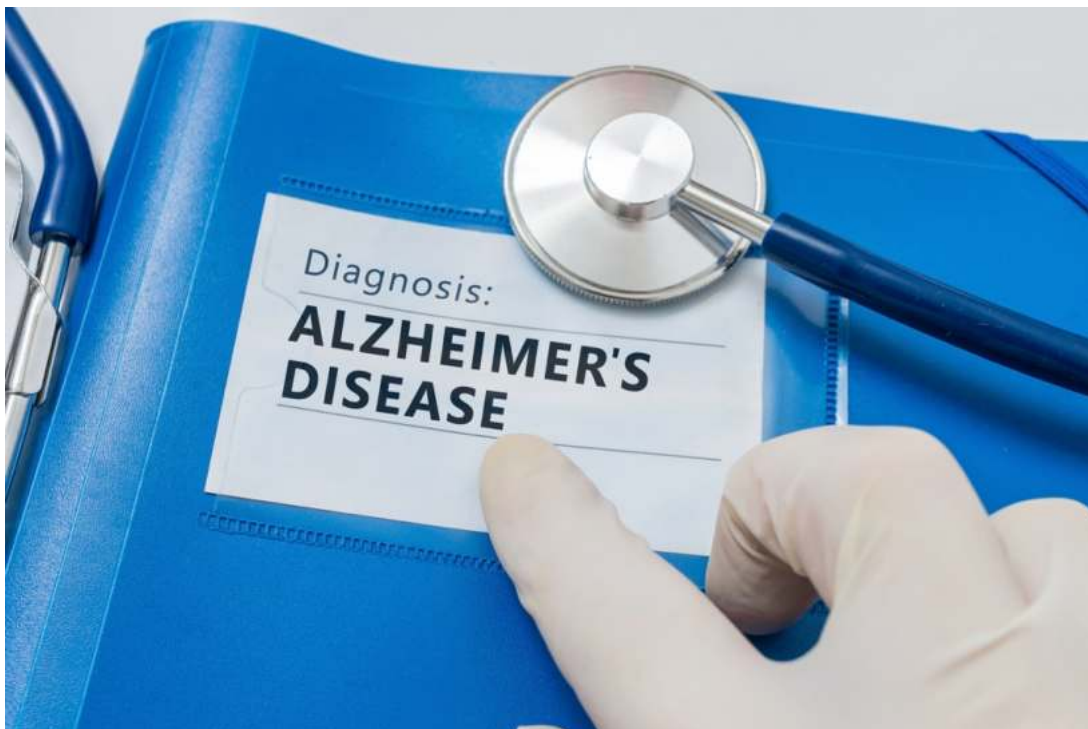
### **If you’re a caregiver:**

- **Arrange companionship.** Schedule family and friends to visit in shifts — and stay overnight, if possible.
- **Work with the nurses.** See if they’d like your help in encouraging the person to eat, stay hydrated, and to participate in rehabilitation therapy.
- **Be vigilant.** If you notice signs of confusion, memory problems, or personality changes, let the nurses or physicians know immediately.





- Cognitive and neuropsychological tests to evaluate thinking (cognitive) function. There are many types of tests that measure thinking skills such as memory, orientation, reasoning and judgment, language skills, and attention.
- Neurological evaluation of memory, language, visual perception, attention, problem-solving, movement, senses, balance, reflexes and other areas.
- Brain scans such as a CT or MRI to check for evidence of stroke or bleeding or tumor or hydrocephalus or PET scans which can show patterns of brain activity and if the amyloid protein, a hallmark of Alzheimer's disease, has been deposited in the brain.
- Laboratory tests such as simple blood tests can detect physical problems that can affect brain function, such as vitamin B-12 deficiency or an underactive thyroid gland. Sometimes the spinal fluid is examined for infection, inflammation or markers of some degenerative diseases.
- Psychiatric evaluation by a mental health professional can determine whether depression or another mental health condition is contributing to the symptoms.



# Dementia Sensitive



**D**EMENTIA SENSITIVE means being able to spot the signs of dementia and addressing the problem or assisting the caregiver to address the problem.

One of the most devastating components of dementia is the inability to identify the problem until a triggering event happens. Sometimes a family will not know a problem exists until something happens that makes the realization of dementia irrefutable. There may be a lapse in judgment that places family finances in jeopardy or the individual in a dangerous position.

Early identification is key.

Perhaps the most alarming part of dementia is the unanticipated onset. It can be gradual or it can be sudden. Often the event that makes friends, family and professionals sit up and notice is some negative outcome where the person with dementia drops the ball. The **National Endowment for Financial Education** surveyed more 2,000 adults and found that in cases where a family member suffered cognitive decline:

- 47 percent failed to pay bills, or paid them late.
- 35 percent made reckless purchases.
- 21 percent had emptied their savings accounts.

The ten signs of loss of cognitive functioning from the Alzheimer's Association include:

1. Memory loss that disrupts daily life.
2. Challenges in planning or solving problems.
3. Difficulty completing familiar tasks at home, at work or at leisure.
4. Confusion with time or 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 and personality.

It is important to realize that everyone forgets something sometime, and items may be misplaced by a person who is not in cognitive decline. The warning signs are behaviors that become repeated patterns to such a degree that life is disrupted, and functioning becomes increasingly difficult.

In many disciplines, such as law, it is critical that a professional be dementia sensitive and recognize that a person with dementia may have the capacity to engage in one decision-making activity but not in another depending on the complexity of the problem being addressed and the decline experienced by the individual. A person may have the ability to engage in making an advance directive for health care but may not be capable of making a will. Being sensitive to levels of cognitive engagement required for persons with dementia to be involved in decision-making makes it imperative for each profession to establish standards for its members to know appropriate ways to engage the person with dementia.

Likewise it is also important to recognize signs of undue influence one person might exert over another who is in cognitive decline and to guard against unwittingly engaging in financial of a person who has dementia. Professional and lay caregivers must be extra vigilant to protect a person with dementia from persons who would take advantage of them and to understand how to acquire the authority necessary to provide that protection.

Subsequent publications will address these issue in more depth.





# Dementia Responsive



**D**EMENTIA RESPONSIVE behaviors require a good understanding of the services that are available to help the person with dementia and his or her caregiver(s) so that appropriate referrals may be made and services located and useful information accessed.

A truly dementia responsive professional service clearly sees the caregiver as “the invisible second patient” as referred to by Henry Brodaty and Marika Donkin in the 2009 NIH research paper titled Family Caregivers of people with dementia. That paper can be viewed at:<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3181916/>

Recognizing the caregiver as the invisible second patient would open the door to a more realistically effective service model that identifies meeting the needs of the caregiver as necessary as those of the care recipient in order to keep the entire caregiving plan afloat.

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Perhaps the most exasperating problem a caregiver faces is not knowing where to get help. A study published by Michigan Family Review in 2013 titled Understanding Resource Needs of Persons with Dementia and Their Caregivers provides an insightful overview of the differing challenges caregivers face in the different stages of care and can help the professional understand that the needs of a person with a new diagnosis may be different from those of a person in the mid or later stages of caring for a loved one with dementia. That report can be viewed at:

[http://digitalcommons.wayne.edu/cgi/viewcontent.cgi?article=1000&context=pharm\\_healthcare](http://digitalcommons.wayne.edu/cgi/viewcontent.cgi?article=1000&context=pharm_healthcare)

If studies of this nature were taken to heart models of caregiver support might be developed recognizing the most pressing needs of caregivers at various stages of decline for the care recipient. A dominant theme in this study is what one caregiver called the “endless loop” of struggling to find resources. As professionals we need to ask how we can close that loop to provide responsive services.



An excellent resource for persons with dementia and their caregivers is the local Aging and Disability Resource Center (ADRC) where the individuals live.

The Administration on Aging (AoA) began the Aging and Disability Resource Center model to serve as a single point of entry into the long-term services and supports system for older adults, people with disabilities, caregivers, veterans

and their families. ADRCs were established to provide in every community a trusted source of information where people of all incomes and ages could turn for the full range of long-term support options and smooth access to public long-term support programs and benefits. In Alabama and many locations in the country Area Agencies on Aging (AAAs) have helped pilot ADRCs for more than a decade, and nearly three-quarters of America's AAAs perform ADRC functions in their communities as of 2014.

The AAA/ADRC serving Blount, Chilton, St. Clair, Shelby and Walker Counties is The Middle Alabama Area Agency on Aging. Contact that agency and ask for their guide THE BOOK, A Guide for Help, Information, and Resources.

Middle Alabama Area Agency on Aging



The cover of the guide "THE BOOK" features a photograph of an elderly man in a wheelchair, an elderly woman sitting next to him, and a caregiver standing behind them. The photo is framed by a large, stylized arrow graphic pointing to the right, with a green and blue color scheme. Below the photo, the title "THE BOOK" is written in large, bold, black letters. Underneath the title, the subtitle "A GUIDE FOR HELP, INFORMATION, AND RESOURCES" is written in smaller, bold, black letters. At the bottom of the cover, contact information is provided: "Office: (205) 670-5770", "Toll Free: (866) 570-2998", and "Website: www.m4a.org".

## Other Resources

**University of Alabama at Birmingham's Alzheimer's Family Program:**

<http://www.uab.edu/medicine/aging/alzheimer-family-program>

**Alzheimer's Association:**

[http://www.alz.org/about\\_us\\_about\\_us\\_.asp](http://www.alz.org/about_us_about_us_.asp)

**Alzheimer's of Central Alabama:**

<http://alzca.org>

**Assessment Of Older Adults With Diminished Capacity: A Handbook For Lawyers:**

[https://www.americanbar.org/groups/law\\_aging/resources/capacity\\_assessment.html#forjudges](https://www.americanbar.org/groups/law_aging/resources/capacity_assessment.html#forjudges)

**Judicial Determination of Capacity of Older Adults in Guardianship Proceedings:**

[https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2011\\_aging\\_bk\\_judges\\_capacity.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2011_aging_bk_judges_capacity.authcheckdam.pdf)

**Assessment of Older Adults with Diminished Capacity: A Handbook for Psychologists:**

[https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/2011\\_aging\\_bk\\_psych.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/2011_aging_bk_psych.authcheckdam.pdf)

**National Institute on Aging, Alzheimer's Disease Education and Referral Center:**

<https://www.nia.nih.gov/alzheimers>

**Alzheimer's Reading Room:**

<http://www.alzheimersreadingroom.com>

# Are you a caregiver caring for someone with Alzheimer's Disease or Dementia?

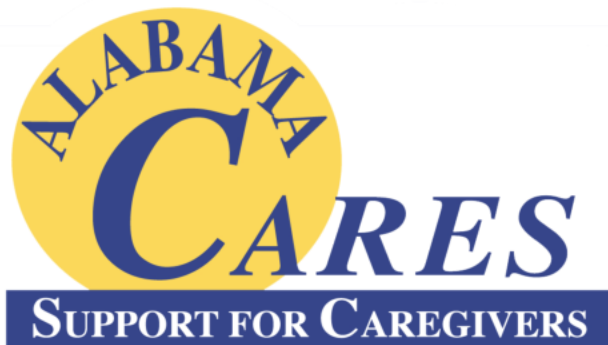
The Alabama Cares program provides temporary supportive services that can assist you as a caregiver as you care for your loved one with Alzheimer's Disease or Dementia. There is no income requirement for the Alabama Cares program. Alabama Cares can help with:

Offering Local Support Groups

Providing "Dementia Friendly" Training

Providing Alzheimer's and Dementia Education

Providing Paid Respite



CAREGIVERS CAN GET SUPPORT WITH INFORMATION,  
ACCESS ASSISTANCE, EDUCATION, AND RESPITE SERVICES.

**CALL 1-800-AGE-LINE TODAY**