



2015 DEMENTIA RESOURCE GUIDE



**HELP FOR THOSE IN NEED OF
INFORMATION & SERVICES**



DEMENTIA RESOURCE GUIDE

2015 DEMENTIA RESOURCE GUIDE

Presented to Alabama by:

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About this Resource Guide

This Resource Guide was created to assist you if you, a friend or family member has a diagnosis of dementia. It is normal to have questions with a diagnosis of dementia. This Guide provides you with some basic information, and may help someone in Alabama who is not sure where to take their questions. The Information in this guide can also be found online at www.alabamadementia.gov.

The goal of this guide is to point you in the right direction about a specific topic related to dementia. Many common questions you may want to ask are provided. There are a lot of resources related to dementia available on the Internet and through the public library. We have included links to the Internet and provided a toll-free telephone number for more information. The contact information provided in this guide was current, as of January 2015.

This guide provides an overview about common types of dementia, and the types of healthcare providers you may work with. The Guide also offers tips on how to talk with healthcare providers. We have also tried to explain some confusing terms used when talking about dementia. The Guide then describes some basic information related to the diagnosis and treatment of dementia. The Guide also describes types of care and housing options, agencies that provide support to individuals with dementia and their caregivers. Information about health care funding options available to individuals and caregivers is also provided.



Resource Telephone Numbers

Alabama's Aging Disability Resource Center **1-800-243-5463**

A one stop access point for information and services to help adults with disabilities and their caregivers find the resources they need.

Alabama Cares Program Coordinator **1-334-242-5772**

Offers support for caregivers across the state by providing information, assistance, counseling, respite, and supplemental services.

Alabama Lifespan Respite Resource Network **1-866-737-8252**

A statewide program to connect caregivers to respite resources.

Alabama Elderly & Disability Waiver Program **1-800-243-5463**

A Medicaid program designed to provide home-based services to seniors and those with disabilities who would otherwise qualify for long-term care.

Alabama State Health Assistance Program **1-800-243-5463**

Provides local assistance for Medicare beneficiaries and their caregivers to better understand Medicare benefits.

Elder Justice & Advocacy **1-877-425-2243**

Provides education and awareness on the rights of elders, elder abuse and prevention, and economic security issues.

Long-term Care Ombudsman (Advocate) **1-334-353-8689**

The Ombudsman (advocate) protects the rights of long-term care residents, and assures they receive fair treatment and quality care.

Senior Rx (Prescription) **1-800-243-5463**

Prescription drug assistance program to help Alabamians receive free prescription drugs from pharmaceutical companies.



Common Terms

The words used in healthcare can be confusing to many. When you do not understand medical terms, do not feel bad about asking that the information be explained to you in words that you will understand. A few common terms are described below, but others can be found online.

ADLs: Activities of Daily Living (ADLs) are activities performed for self-care, such as bathing, dressing, toileting, cooking, laundry, or shopping.

Aphasia: A disorder of communication, including speaking, understanding what others are saying, or naming objects.

Cognition: The process of knowing something.

Delirium: Confusion and changes in brain function that appear rapidly. Often short term and should not be confused with dementia.

Dementia: A change in mental processes that can include memory problems, changes in personality, and changes in reasoning (See “What is Dementia?”).

Diagnosis: The cause of a medical problem.

Gait: A medical term for walking.

Incontinent: Difficulty or inability to control urine in the bladder, or to keep feces in the rectum. There are different types and causes.

Memory: Ability to recover (remember) information from the past. With some forms of dementia, short-term (recent) memory is lost, while long-term (older) memory remains.

Prognosis: The most likely outcome of the disease process.

Vascular: Relating to the blood vessels.



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What is Dementia?

Dementia is not easy to describe or understand. There are many types and causes of dementia, and not all types of dementia present the same way. Dementia usually happens in older age and is most easily described as changes in memory, thinking, language, judgment, and behavior. Most causes of dementia cannot be stopped and will progress over time.

When we hear the word dementia we often think about someone being forgetful; however, forgetfulness does not mean one has dementia. Forgetfulness that gets worse over time, or changes in one's ability to do tasks they had done before without help is a concern. Changes in behavior like getting mad or becoming fearful is also a concern.

Some of the common types of dementia are described on the Types of Dementia page. You should ask your healthcare providers questions about the specific type of dementia you or your loved one has, how that type of dementia is best treated, and how it progresses over time.

Common Questions

- ➔ **Have I considered other medical or mental causes?**
- ➔ **How will the dementia change over time?**
- ➔ **What treatments are available for this type of dementia at this time?**
- ➔ **What healthcare and legal decisions should we make now?**

On-line Resources

www.AlabamaDementia.gov/definition.html

Contacts

**Alzheimer's Association 24/7 Helpline:
1-800-272-3900**



Types of Dementia

There are a number of types of dementia. Some of the more common diagnoses are described here. **Do not be afraid to ask your healthcare provider questions about a specific type of dementia.**

- **Alzheimer's Disease:** The most common type of dementia. Occurs most often in old age, the disease slowly and progressively destroys the brain. As the disease progresses, new symptoms will be present and old symptoms will worsen.
- **Vascular Dementia:** Sometimes called Multi-infarct dementia. This type of dementia is the result of small or large strokes, or poor blood supply to the brain.
- **Dementia with Lewy Bodies:** Common in individuals with Parkinson's Disease or Alzheimer's Disease, this form of dementia affects thinking, reasoning, and movement.
- **Mild Cognitive Impairment:** Problems with memory are usually the most common symptom. For some, memory improves over time, yet for others it gets worse. This diagnosis can often be the first step to a diagnosis of Alzheimer's Disease.
- **Frontotemporal Dementia:** Also known as **Pick's Disease**, this type of dementia affects more men than women and is common between 40 to 60 years of age. Behavioral changes in personality, judgment, language, and memory are common.
- **Normal Pressure Hydrocephalus:** Caused by a build up of cerebrospinal fluid in the brain, which causes enlargement. Symptoms are often confused with Alzheimer's Disease and Parkinson's Disease. Symptoms improve best when treated early.
- **Parkinson's Disease Dementia:** Associated with Parkinson's Disease and occurs later in the diagnosis. This type of dementia is similar in characteristics to Dementia with Lewy Bodies.



Types of Healthcare Providers

Counselor: Works with the individual and/or his or her caregiver/family to address issues associated with the diagnosis, including: anxiety, communication, coping, depression, emotions, family dynamics, grief, and others. Counselor types may include Family Therapists, Mental Health Counselors, Psychologists, Rehabilitation Counselors, and Social Workers.

Geriatrician: A physician (M.D. or D.O.) who specializes in aging.

Internist: A physician (M.D. or D.O.) who specializes in adult medicine.

Neurologist: A physician (M.D. or D.O.) who specializes in the nervous system, including the brain, spinal cord, muscles and nerves.

Neuropsychologist: A neuropsychologist is a psychologist who specializes in behaviors related to brain function and brain structure.

Occupational Therapist (OT): An OT works to help individuals engage in meaningful activity designed to improve or maintain the highest possible level of independence and quality of life. Activities frequently focus on activities of daily living (also known as ADLs).

Pharmacist: A pharmacist dispenses and provides information about drugs/medicine. Pharmacists can answer questions about different types of medicines and how they interact in the body.

Primary Care Provider: The physician (M.D. or D.O.) or non-physician (Nurse Practitioner or Physicians Assistant) that a patient usually sees for general health concerns.



Types of Healthcare Providers (Continued)

Psychiatrist: A physician (M.D. or D.O.) who specializes in mental health.

Physical Therapist (PT): A PT works with the individual to promote functional ability and quality of life. Activities frequently focus on exercise, movement and safety.

Social Worker: A professional who seeks to improve the quality of life and well being of individuals, families, and communities.

Speech-language Pathologist (SLP): A SLP not only addresses speech and communication disorders, but also addresses swallowing disorders (also known as dysphagia).



Communicating with Providers

Communicating with a healthcare provider can be intimidating for some, especially when discussing the healthcare of a loved one. Healthcare providers chose their profession because they wanted to help others—like you. So, **do not be afraid to ask questions.**

When preparing for a visit with a healthcare provider:

- 1) Ask them, “What information you need to bring to the first visit?”
- 2) Take a list of your concerns and questions, especially those related to that professional’s area of expertise. If you ask questions that are not in their area of expertise, they will refer you to someone who can answer. If you do not take a list of concerns or questions, you may forget.
- 3) Take a list of all medication, including the dose and times per day. Your pharmacist can help you make this list. Or, you can take the medicine bottles with you to the appointment.
- 4) If you do not understand something the provider is trying to explain to you, simply tell them that you do not understand. Help the provider by telling them what you do understand, so that they can focus on the parts that you don’t. It is important to stay calm if you do not understand everything. Write things down, if that helps. Or, if you are at the provider’s office and have a cellular phone that records, ask if you can record what they are trying to explain on your telephone.
- 5) If you understood something when they explained it to you, but you have forgotten—ask again.
- 6) Take good notes, especially with appointment times, things to bring with you, medication, activity and exercise instructions, and issues related to safety.



Caregiver Support

Caregiving can be both rewarding and stressful. Over time, the stress of being a caregiver for someone with dementia can become difficult. Too often, caregivers don't make time for themselves, which can result in anger, sadness, or changes in their own physical health.

If you are a caregiver, it is important to make a plan, so that you can take breaks when needed. If you notice changes in your own health or well being, it is important to seek support so that both you and your loved one stay as healthy and well as possible.

Your local Area Agency on Aging (AAA) is a good place to start. They may offer classes for caregivers, and can also connect you to resources such as adult day services, caregiver support groups, sitter services, and other helpful services. Caregiving is hard, so make sure you take care of yourself too.

Common Questions

- ➔ Who can help with caregiving duties?
- ➔ Can my local AAA provide support?
- ➔ When I need a break, who will provide care?
- ➔ If I hire a caregiver, what skills do they need to have to help?
- ➔ Do I have a plan to make sure I give myself the time and attention I need?

On-line Resources

www.AlabamaDementia.gov/support.html

Contacts

Alzheimer's Association 24/7 Helpline:
1-800-272-3900



Diagnosis of Dementia

Finding out if someone has dementia is not always easy. There are many health issues that can cause changes in memory, so one should not assume dementia is the problem when someone is forgetful.

When someone begins to show changes in memory, it is important that they see their primary care provider. Ruling out other possible causes, like depression, will need to be checked.

Your primary care provider may recommend that a specialist, like a neurologist, psychiatrist, or neurologist, be seen. Once a diagnosis of dementia has been made, a treatment plan can be built based on the type and stage of dementia.

Receiving a diagnosis of dementia is difficult. It is important to ask your healthcare provider about the future, so that you can make a plan for how to best move forward.

Common Questions

- ➔ Does my loved one need to see a specialist?
- ➔ What services are available to provide assistance?
- ➔ What treatment options are available?
- ➔ If one treatment option doesn't work well, are there other options?
- ➔ Is there a local support group in my area?

On-line Resources

www.AlabamaDementia.gov/diagnosis.html

Contacts

Alzheimer's Association 24/7 Helpline:
1-800-272-3900



Medication and Dementia

Individuals with dementia and their caregivers should become familiar with both prescribed and non-prescribed medications being taken. Becoming familiar with common side effects of medication, and how medications can negatively interact is important.

Keeping a list of all drugs taken, whether prescribed or over-the-counter, can be helpful in managing medication. Writing down the drug name, the amount of drug taken, and how often the drug is taken is important. Your pharmacist can create this list for you if you need assistance.

When medication is prescribed, ask the healthcare provider or pharmacist about side effects and drug interactions, and when you should contact them if an unexpected reaction is noticed. Make sure you add newly prescribed drugs to your medication list, and remove drugs that are no longer being prescribed or taken.

Common Questions

- ➔ **Are there any special instructions to follow? Do I understand those instructions?**
- ➔ **Is a generic (and possibly cheaper) version of the medication available?**
- ➔ **How will we know if the drug is helping?**
- ➔ **Have I made a list of medication and shared it with healthcare providers?**

On-line Resources

www.AlabamaDementia.gov/medication.html

Contacts

- ◆ **My local pharmacy telephone number is: _____.**
- ◆ **My local 24 hour pharmacy telephone number is: _____.**



Activity and Dementia

Functional Activity Considerations

Being active is important for both mental and physical health. Having a diagnosis of dementia does not mean giving up all of the activities you love. Staying active enhances quality of life, and may distract from behaviors like wandering or getting upset.

Activities like taking care of yourself, working on a hobby, and playing games have been shown to improve cognition. Activity that is meaningful to the person and is done in a safe place is important. Activities should be done at a specific time of the day, and in a set order, to help with memory and decrease confusion. An Occupational Therapist (OT) can create an activity plan based on what your loved one is interested in and able to do. An OT may also provide help on other ways to improve memory and function.

Common Questions

- ➔ **What type of activity program is safe and appropriate?**
- ➔ **How much guidance/physical assistance will he/she need?**
- ➔ **What equipment will be needed?**
- ➔ **Will the OT teach me how to manage the activity plan?**
- ➔ **How can I work these activities into a daily routine?**

On-line Resources

www.AlabamaDementia.gov/activity.html

Contacts

**Alzheimer's Association 24/7 Helpline:
1-800-272-3900**



Exercise and Dementia

Exercise Considerations

Exercise is important for both mental and physical health. Activity and exercise are important to maintaining one's balance, flexibility, strength, and endurance. All of these things help someone stay safely mobile.

Physical exercise has been shown to improve memory. Making sure exercises relate to function and are done in a safe place is important. Exercises should be done at a specific time of the day, and in a set order, to aid memory and avoid confusion. Before starting any exercise program you should talk to your physician or physical therapist (PT). A PT will help make an exercise program specific to your loved one's ability.

Common Questions

- ➔ **What type of exercise program is safe and appropriate?**
- ➔ **How much guidance/physical assistance will he/she need?**
- ➔ **What equipment will be needed?**
- ➔ **Will the PT teach me how to manage the exercise plan?**
- ➔ **How long and hard should he/she workout?**

On-line Resources

www.AlabamaDementia.gov/exercise.html

Contacts

Alabama Physical Therapy Association:
1-800-999-2782 (x3284)



Nutrition and Dementia

Eating right is important to stay healthy. Not getting the right amount and type of nutrition can lead to behavior changes. Following a healthy nutrition plan is important.

Mealtime can be made easier by:

- Eating in a calm and quiet place
- Avoiding things that take attention from the meal
- Serving food that is not too hot or too cold
- Don't serve too many foods at one time
- Allowing for extra time to eat if needed

Prepare foods that are easy to chew and swallow. If it appears that food and drinks are hard to swallow, ask your physician about a swallowing test by a speech-language pathologist (SLP) or an occupational therapist (OT). They can make an eating and swallowing plan specific to your loved one.

Common Questions

- ➔ **If swallowing is an issue, is a swallowing evaluation needed?**
- ➔ **Have I reduced distractions during mealtime?**
- ➔ **Have I planned meals that provide proper nutrition?**
- ➔ **Am I encouraging independence during mealtime? Can using a straw or eating with hands help?**
- ➔ **Can a SLP or OT help with our meal time issues?**

On-line Resources

www.AlabamaDementia.gov/nutrition.html

Contacts

- ◆ **Alzheimer's Association 24/7 Helpline: 1-800-272-3900**
- ◆ **Family Caregiver Alliance: 1-800-445-8106**



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Driving and Dementia

Deciding when driving is unsafe for someone with dementia can be hard, especially if the driver is not aware that there is a problem. For many, driving is important. But, allowing someone who is unsafe to drive puts them and others at risk.

Suggestions:

- Talk to them about your concern for their safety
- Discuss options to meet their needs that require driving (i.e., shopping, church, social activities) and how those needs can be met
- Consider asking a physician to provide a prescription that “No Driving is Allowed” when driving becomes unsafe.

You may want to consider an assessment of your loved one's driving from an occupational therapist or driving specialist.

Common Questions

- ➔ **Is my loved one safe to continue driving?**
- ➔ **Have I planned to have a conversation about not driving?**
- ➔ **Do I need to talk to their physician or a specialist about their driving?**
- ➔ **Have I considered options for other transportation?**
- ➔ **Can my local Area Agency on Aging help?**

On-line Resources

www.AlabamaDementia.gov/driving.html

Contacts

www.AlabamaDementia.gov/driving.html



Legal Issues

Common Questions

- ➔ **Have I gathered legal documents, bank records and other financial and legal information?**
- ➔ **Is there an attorney in my area who specializes in elder law?**
- ➔ **Who will have decision making authority on issues related to finances and health?**
- ➔ **Have I spoken to the bank?**
- ➔ **Can my local AAA help me?**

There are a number of legal things that need to be considered early in the diagnosis of dementia. Make decisions for healthcare, money, property, and other important issues early. This allows the individual with dementia to be involved in the decision making.

If the individual is able to make legal decisions, it is important they be involved in the process. However, if they do not understand the importance of the issue being discussed, you may need to seek legal advice from an attorney.

An attorney can help you complete documents that make sure the wishes of your loved one are carried out. They can also help you plan and address needs when the person is no longer able to make their own decisions. An attorney can guide you on legal actions that need to be taken.

On-line Resources

www.AlabamaDementia.gov/legal.html

Contacts

www.AlabamaDementia.gov/legal.html



Staying at Home

Staying at home (Aging in Place) for as long as possible is the goal for many individuals and their family. Staying in a familiar place is comforting for many, and may decrease confusion. Individuals with dementia may benefit from changes to their home that could help them stay at home longer. Examples are:

- Change paint colors to make things easier to see
- Put safety bars in the bathroom
- Make things in the kitchen safe to avoid burns, cuts, and fires
- Move furniture and other things that could cause falls

Occupational therapists who make home evaluations and safety checks can help. Many professionals like architects, builders, and interior designers can also provide assistance. Use licensed or certified providers when possible.

Common Questions

- ➔ **What is limiting us from keeping our loved one at home? Can these issues be addressed?**
- ➔ **How will aging in place benefit me, my family, and my loved one?**
- ➔ **What are the costs of modifying our environment?**
- ➔ **Does modifying a home environment meet my needs and those of my loved one?**

On-line Resources

www.AlabamaDementia.gov/staying.html

Contacts

- ♦ **National Association of Home Builders: 1-800-368-5242**
- ♦ **American Occupational Therapy Association: 1-800-SAY-AOTA**



Adult Day Services

Medical and Social Models of Service

Adult day care bridges the gap between living alone and high levels of care. Adult day services may offer help for caregivers who are unable to watch their loved one during the day. Adult day services provide safe and proper care.

There are at least two kinds of day care models, social and medical. Social models of adult day services are designed to provide activities that will allow participants to use their cognitive, motor, language, and social skills. Medical models of adult day services provide health and rehabilitation service, in addition to social interaction activities. The type of adult day services you seek may be determined by the level of care required. Speak to a facility representative to determine if the fit is right for you and your loved one.

Common Questions

- ➔ **Is the facility safe and meet fire and health codes?**
- ➔ **Is the atmosphere friendly (How do you feel when you walk in)?**
- ➔ **Is the cost affordable?**
- ➔ **Are appropriate activities planned each day?**
- ➔ **Do days and times of service meet your needs?**

On-line Resources

www.AlabamaDementia.gov/dayservices.html

Contacts

- ◆ **Alabama Department of Senior Services: 1-334-242-5743**
- ◆ **Eldercare Locator: 1-800-677-1116**
- ◆ **Alabama Alzheimer's Assoc.: 1-800-272-3900 for a local referral**



Home Health Care

Getting medical care at home may be an option for some. This option helps many to stay at home longer. Home Health Care is a benefit under Medicare (Part A hospital benefit), and may also be covered by private insurance. Home Health service must be related to a current diagnosis that makes someone homebound. Homebound means that leaving the home requires a “taxing effort”, and must be ordered by a physician.

Home health agencies may offer both medical and non-medical services. Health services include skilled care provided by a nurse, certified nurse aid, occupational therapist, physical therapist, speech-language pathologist and/or medical social worker. Home health care agencies may offer other services, like sitters and housekeepers, for a fee.

Common Questions

- ➔ **Does the individual qualify as homebound?**
- ➔ **Are skilled health care services required?**
- ➔ **Does the individual have Medicare or other insurance to cover the cost?**
- ➔ **Is it safe for the individual to be home? Or, will home care improve the safety of the individual at home?**

On-line Resources

www.AlabamaDementia.gov/homecare.html

Contacts

National Association for Home Care & Hospice: 1-202-547-7424



Assisted Living Environments

An Assisted Living Facility is a long-term care option that provides individuals personal care and assistance with daily activities as needed.

An Assisted Living community provides housing, meals, housekeeping, medication management, transportation, and social activities. Many facilities also have Specialized Care Assisted Living Facilities (SCALF) that can provide more specialized support to individuals with dementia. Residents are assessed upon move in, or any time there is a change in condition. The assessment is used to develop an Individualized Service Plan.

The costs for residency in a facility may vary and require private pay, and it is important to get a full breakdown of charges to determine if an Assisted Living long-term care facility is an option.

Common Questions

- ➔ Do I know anyone with personal experience with this facility?
- ➔ Do they have SCALF?
- ➔ Is the facility licensed?
- ➔ Does your loved one's physician provide service at this facility?
- ➔ Is the cost within my budget?
- ➔ Have I reviewed complaints about this facility?

On-line Resources

www.AlabamaDementia.gov/assisted.html

Contacts

Assisted Living Association of Alabama: 1-800-826-9410



Hospice Care

Hospice care focuses on making sure that your loved one is comfortable and supported at the end of life. Hospice care also supports caregivers and family members during this difficult time.

An individual is considered to be in their last six months of life before hospice services are provided. A physician must order hospice care. The focus of hospice is to provide care that ensures comfort and dignity at the end of life. But, healthcare services similar to those available in home health care are available.

For patients with Medicare, hospice services are covered under Part A of their health care benefits. Once admitted to hospice services, caregivers will have access to respite support services that may be covered by Medicare.

It is important to remember that hospice services also provide counseling, spiritual/religious support, and social work services to the family.

Common Questions

- ➔ **What hospice agencies are located nearby?**
- ➔ **Does my loved one's physician agree that hospice services are appropriate?**
- ➔ **Do I know someone locally who has used the hospice service who can guide me?**
- ➔ **Have I asked a hospice care representative about the services they provide?**

On-line Resources

www.AlabamaDementia.gov/hospice.html

Contacts

- ◆ **Alabama Hospice and Palliative Care Organization: 1-334-421-8884**
- ◆ **National Association for Home Care & Hospice: 1-202-547-7424**
- ◆ **My Local Area Agency on Aging telephone number is:**



Respite Care Options

Respite is a word describing a short period of rest or relief from something difficult. Respite care provides caregivers with temporary rest from their care giving duties. Too often caregivers overwork themselves to the point where their own health or relationships begin to decline. Sometimes caregivers need a break too-- and that is okay.

Taking the time to relax, and focusing on yourself or family and friends can be hard for some caregivers. Knowing that your loved one is in a safe and supportive environment during this break time makes your experience much better. Arranging respite care takes planning. Respite care is commonly offered through in-home care services, adult day services, and residential facilities. If your loved one is receiving hospice care, Medicare may cover respite care on a short-term basis.

Common Questions

- ➔ **Have I planned for emergency care if I have to be away?**
- ➔ **Have I considered my own health as a caregiver?**
- ➔ **Have I planned for the cost of respite care?**
- ➔ **Can my Area Agency on Aging provide me advice?**
- ➔ **Do other local caregivers have advice they can offer me?**

On-line Resources

www.AlabamaDementia.gov/respites.html

Contacts

- ◆ **Alabama Lifespan Respite:
1-866-RESTALA**
- ◆ **Alabama Respite Connections:
1-256-739-8621**



Long Term/Nursing Home Care

For those who have needs beyond those that can be provided by adult day services, home health care, or other residential care, or when it becomes too difficult on the caregiver to provide adequate and safe care, long-term care (also known as nursing home care) may be required.

There are more than 220 nursing homes in Alabama with a total of more than 26,000 beds. Medicare.gov recommends the following when finding a nursing home that meets your needs:

- 1) Find nursing homes in your area.
- 2) Compare the quality of the nursing homes you are considering.
- 3) Visit the nursing homes you are interested in, or have someone visit for you.
- 4) Ask specifically about dementia care services.
- 5) Choose the nursing home that meets both yours and your loved ones needs.

Common Questions

- ➔ **Do I know anyone with personal experience with this facility?**
- ➔ **Do they have a dementia unit?**
- ➔ **Does your loved one's physician provide service at this facility?**
- ➔ **Is the cost within my budget?**
- ➔ **Have I reviewed complaints about this facility?**

On-line Resources

www.AlabamaDementia.gov/longterm.html

Contacts

- ◆ **Alabama Nursing Home Assoc:**
1-334-271-6214
- ◆ **State Ombudsman (Advocate):**
1-334-242-5743



Psychiatric Inpatient Care

At some point, someone with dementia may have need for assessment and treatment at an inpatient psychiatric center. This type of care may be needed if your loved one has another mental health condition besides dementia. Using this type of hospital is done to help find out what your loved one needs, not to "put them away." Your loved one's primary care provider will be able to guide you if this option needs to be considered.

Often, inpatient psychiatric care is beneficial when patients have severe agitation, poor sleep, poor appetite, or other conditions. The facility will evaluate your loved one's mental and physical health, and suggest a treatment plan.

Other than psychiatrists (physicians who specialize in mental health), healthcare providers who may work with your loved one in the facility might include nurses, social workers, psychologists, occupational therapists, recreation therapists and others.

If your loved one is admitted to a psychiatric inpatient facility, begin working with the social worker early to determine what will happen next.

Common Questions

- ➔ **Do I have copies of all documents the facility requires?**
- ➔ **Do I know who will be responsible for finances and other arrangements?**
- ➔ **Do I have copies of medical and psychiatric records to share?**
- ➔ **Do I know which next-of-kin will interact with the treatment team?**

On-line Resources

www.AlabamaDementia.gov/psychiatric.html

Contacts

- ◆ **Bryce Hospital (Tuscaloosa): 1-205-507-8000**
- ◆ **Mary Starke Harper Geriatric Psychiatry Center (Tuscaloosa): 1-205-759-0900**
- ◆ **Taylor Hardin Secure Medical Facility (Tuscaloosa): 1-205-556-7060**



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Ombudsman (Advocate) Services

Alabama’s Long-Term Care Ombudsmen are advocates for residents of long-term care facilities (Nursing Homes, Board & Care Homes, Specialty Care, are Assisted Living Facilities). Ombudsmen work to protect the health, safety, welfare and rights of Alabama’s long-term care residents.

Ombudsmen investigate and resolve complaints, ensure that residents are receiving quality care, educate residents, their families, and facility staff about residents’ rights, provide information to the public, and represent residents interests by working to change laws, regulations and policies that affect those who live in long-term care facilities.

Anyone can use Ombudsman services, including residents, staff of long-term care facilities, or friends and family members of residents. A complaint can be filed in writing, by phone, or in person. Do not feel afraid to ask for an Ombudsman’s assistance—they can help.

Common Questions

- ➔ **Do I know who my local Ombudsman is? Do I have their contact information?**
- ➔ **Am I concerned about the care my friend or family member is receiving? If so, have I contacted the Ombudsman?**
- ➔ **Have I clearly explained my concern to the Ombudsman?**

On-line Resources

www.AlabamaDementia.gov/ombudsman.html

Contacts

- ◆ **Alabama Long-term Care Ombudsman: 1-800-AGE-LINE (243-5463)**
- ◆ **Assisted Living Complaint Hotline: 1-866-873-0366**
- ◆ **Elder Abuse Hotline: 1-800-458-7214**



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Area Agency on Aging (AAA)

An Area Agency on Aging (AAA) serves as a resource for older adults and their families and caregivers. One goal of AAAs is to help individuals stay in their homes as long as possible.

Once you have identified the AAA that serves your county in Alabama, you should contact them and ask about the services they offer. Your local AAA may be able to connect you to needed services, such as:

- Meals-on-Wheels
- sitter services
- transportation services.

Your local AAA will be familiar with both state and county services available. They also know about services provided by aging related businesses in your area. AAAs often provide education on aging specific topics to older adults and their caregivers.

Knowing what services your local AAA can provide will assist you in making a plan for the future.

Common Questions

- ➔ What services does my local AAA provide?
- ➔ Can my local AAA recommend a provider for a specific service, like transportation?
- ➔ What available resources are specific to dementia?
- ➔ Is there a local caregiver support group?

On-line Resources

www.AlabamaDementia.gov/aaa.html

Contacts

- ◆ Alabama Department of Senior Services: 1-800-243-5463
- ◆ My local AAA telephone number is:
_____.



DEMENTIA RESOURCE GUIDE

Alabama Department of Senior Services

The Alabama Department of Senior Services (ADSS) provides services and links to services for seniors and their caregivers and families. ADSS works with Area Agencies on Aging to see that an older person's care, health, safety and well-being needs are met. ADSS provides help with:

- Caregiver assistance
- Elder abuse prevention
- Legal issues
- Long-term care issues
- Medicaid
- Medicare and insurance counseling
- Diet and Nutrition
- Ombudsman services
- Help with medicine
- And more!

Your local Area Agency on Aging can also assist you in finding the help that you need.

Common Questions

- ➔ Have I reviewed the services available on the ADSS web-site?
- ➔ Have I contacted my local AAA about resources and services available?
- ➔ Does the ADSS or AAA provide any education programs that might be helpful?
- ➔ Have I planned ahead for the care changes expected with dementia?

On-line Resources

www.AlabamaDementia.gov/adss.html

Contacts

- ◆ Alabama Department of Senior Services:
1-800-AGE-LINE (243-5463)
- ◆ My local Area Agency on Aging telephone number is:



Medicare Coverage

Medicare coverage for dementia is dependent on the patient's need. Medicare covers services that are "reasonable and medically necessary" for the treatment of any condition that has resulted in a loss in abilities and health. Medicare cannot deny services because of a diagnosis of dementia.

Medicare does cover home health care services for patients with dementia, as long as the person requires the skills of a qualified provider.

It is important to understand what you are signing when you are seeking services from a health care provider. You don't want to pay for something that the provider is responsible for paying. Supplemental insurances vary by policy. It is very important to understand what your policy does cover. More importantly what it does not cover.

Common Questions

- ➔ Does the individual have Medicare Part A (Hospital Benefit) and Part B (Outpatient Benefit)?
- ➔ Does the individual have a supplemental insurance policy?
- ➔ Have I discussed coverage with the insurance providers?
- ➔ Are any out-of-pocket expenses required? If so, are they affordable?

On-line Resources

www.AlabamaDementia.gov/medicare.html

Contacts

- ◆ Medicare 1-800-633-4227
- ◆ Blue Cross Blue Shield of Alabama: 1-803-735-1034
- ◆ Cahaba Government Benefit Administrators: 1-877-567-7271
- ◆ Palmetto Government Benefit Administrators: 1-803-735-1034



Medicaid Waiver Program

The Alabama Medicaid Elderly & Disabled Waiver Program is designed to provide services to older adults and others whose needs would qualify for placement in a long-term care facility.

This program is for those who qualify for Medicaid, and would require placement in a long term care facility if they did not get help in their home. The kinds of help available to those who qualify include:

- case management
- personal care
- homemaker services
- companion services
- respite care
- adult day services (where available)
- nutrition and meals.

Waiver program enrollment is limited and a waiting period may be required.

Common Questions

- ➔ Does my loved one qualify for Medicaid ?
- ➔ Does my loved one's current level of care qualify for Waiver Services?
- ➔ Do I have all the documentation (financial, legal, medical) needed to apply for services?
- ➔ Can my local Area Agency on Aging help?

On-line Resources

www.AlabamaDementia.gov/medicaid.html

Contacts

- ♦ Alabama Medicaid:
1-800-362-1504
- ♦ Waiver Services Program:
1-800-243-5463
- ♦ My local Area Agency on Aging telephone number is:



Insurance Coverage

Common Questions

Insurance coverage varies by policy. It is very important to understand what your policy does cover. More important is that you understand what it does not cover. If your loved one does not have Medicare, it is important to get information about coverage.

It is important to understand what you are signing when you are seeking services from a health care provider. You don't want any surprises, and you do not want to pay for something you should not have to.

For questions, contact the insurance provider's customer service department or the insurance agent. Ask about coverage for all conditions, including those associated or commonly associated with dementia.

If your loved one has not started the process for disability eligibility to receive Medicare, it would be a good idea to begin that process now.

- ➔ **Does the individual have an insurance policy to cover health or long-term care?**
- ➔ **Have I asked the insurance provider about coverage?**
- ➔ **Does the individual qualify for Medicare coverage due to disability?**
- ➔ **Are any out-of-pocket expenses required? If so, are they affordable?**

On-line Resources

www.AlabamaDementia.gov/insurance.html

Contacts

- ◆ **Alabama Department of Insurance: 1-334-269-3550**
- ◆ **Blue Cross Blue Shield of Alabama: 1-800-292-8868**



Veterans Administration Homes

Alabama Veterans Administration (VA) Homes may provide living options for veterans with long-term health conditions. There are four VA Homes in Alabama. The VA decides who can receive services. To find out about VA programs, you should contact a facility, or the Department of Veterans Affairs.

Eligibility for services, and the level of funding available, is not the same for everyone. The VA will decide how much funding is available.

The VA offers a number of guides related to housing services, including a Shared Decision Making Worksheet and a Caregivers Self-Assessment Worksheet. These worksheets can help individuals and their caregivers determine what type of care might be best, at a given point in time.

Common Questions

- ➔ Is my loved one eligible for services in a VA facility?
- ➔ What paperwork is required to determine eligibility for VA services?
- ➔ What portion of the services, if any, will be covered by the VA?
- ➔ What VA facilities are near me?

On-line Resources

www.AlabamaDementia.gov/vahomes.html

Contacts

- ◆ Bill Nichols State Veterans Home (Alexander City): 1-256-329-3311
- ◆ William F. Green State Veterans Home (Bay Minette): 1-251-937-8049
- ◆ Floyd E. Tut Fann State Veterans Home (Huntsville): 1-256-851-2807
- ◆ Colonel Robert L. Howard State Veterans Home (Pell City): 1-205-338-6487



Caregiver Tips

Some tips offered by caregivers:

- Discuss important decisions early in the diagnosis of dementia.
- Include family in planning discussions, when appropriate.
- Short-term memories are usually lost first, so have conversations about things in the past they can remember.
- Music from the past can bring back memories, and can be calming.
- When playing games, allow your loved one the time they need to play. If the game becomes frustrating, change to a different activity.
- Keep instructions simple. Few words are sometimes best. Don't add too many steps to instructions. Speak slowly and clearly.
- Don't assume that if you are asked for advice that your loved one cannot make a decision. Even people without dementia ask for advice and like to talk things out with family and friends.
- As memory gets worse, don't argue about things they can't remember—they aren't forgetting on purpose.
- Don't repeatedly ask if they know someone—that can lead to frustration. They may know someone without remembering their name.
- Maintain a daily routine. Change can be frustrating. Let your loved one do what they can for themselves as long as they are safe.
- If drinking with a cup is hard, use a straw so they can suck the liquid. If using a spoon or fork is too hard to use, let them use their hands.
- Anger can be a sign of frustration or pain. Try to recognize pain early and act appropriately.

You can search for more tips on the Internet by searching “tips for working with dementia care.”



Caregiver Checklist

The following items are tasks you might consider completing when a diagnosis of dementia has been made:

- Do I know the specific type and stage of dementia?
- Have I asked the physician about what to expect in the future?
- Have I asked about medication and other treatments available?
- Have I or my family and friends discussed the diagnosis?
- Have we created a list of questions that we need answers for?
- Have I identified the local Area Agency on Aging and made contact?
- Have I created a plan/schedule for:
 - Medication?
 - Activity?
 - Exercise?
 - Nutrition?
- Have I thought about living arrangements?
 - Is staying at home an option? If so, are home modifications needed?
 - What supports are needed (e.g., adult day services, meals on wheels, companion services, respite services, etc.)?
 - Will a caregiver be needed? If so, what arrangements need to be made?
- Have I determined what insurance and financial supports are available? Do I need to discuss this with an insurance provider or banker?
- Have legal issues been addressed?
 - Has a Living Will for health care decisions been created?
 - Who has legal Power of Attorney for non-health issues?
 - Has a Will or Trust been created?
- As a caregiver, am I taking care of myself?
 - Do I have a backup plan if I am unable to provide care?
 - Have I planned time for me?



Searching on the Internet

Not everyone uses a computer. And, it is not always easy to find information on the Internet. If you have a computer with Internet, but don't know how to find information and want to, you might want to go to your public library for assistance. The librarian will be able to help you find the information, and can give you some tips on how to search. If you have a friend or family member who is used to using the Internet to find information, they may be able to help you too.

To search on the Internet you will need to open a web browser on your computer like Google Chrome, Internet Explorer, Safari, or Firefox. Once the browser is open you will have to type in an address at the top of your browser to bring up a search engine. The most frequently used search engines to type in are google.com or yahoo.com or bing.com. Once you type in the search engine address and press the "enter" key you will get a box where you can type in the key words related to your search. For example, if I go to Google and type in the words "dementia AND driving", I will get more than 14 million items. But, the most commonly searched items will be listed first. In this case, the top websites were: *Dementia & Driving* from the Family Caregiver Alliance, and *Dementia & Driving Resource Center* from the Alzheimer's Association.

If you do not find the information you are looking for, you can change your search words. For example, if searching "dementia AND driving AND Alabama Law", I would find almost 400,000 items. The top two are more specific to Alabama state driving laws for seniors and elderly drivers, and information from the National Highway Traffic Safety Administration.

If you know the web address, you can type that into the search area. For example, you can type in "www.alabamadementia.gov" to go to the website of this resource guide.

It is not good if you get upset trying to find information on the Internet. If you do not have access to a computer, or are having difficulty finding the information you are seeking, you can always call 1-800-AGE-LINE for help.



Disclaimer

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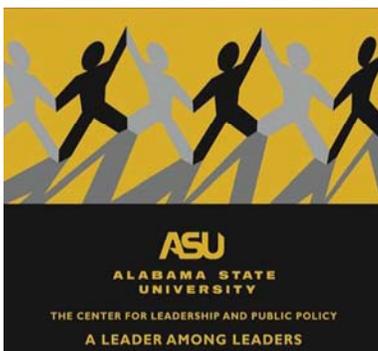
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