



Caregiver Quick Guide

This quick guide exists to assist caregivers in taking initial steps towards supporting their loved one living with dementia and accessing caregiver resources.





Caregiver Quick Guide

Initial Steps After Diagnosis

AFTER A DIAGNOSIS

It is important to begin learning more about the disease, identifying members of the diagnosed individual's care team and collectively developing a plan of care. Also, if the diagnosed individual is able to understand, it is important to respect their right to know and involve them as much as possible in future planning and decisions. Upon receiving the diagnosis, you may choose to share the diagnosis with family, friends, or members of your faith organization.

If you are a caregiver and still employed, you may want to talk with your employer to learn about policies within your place of employment that supports your new caregiver role.

Since your physician is an important part of your care team, you may want to ask additional questions:

- What stage of Alzheimer's disease is he or she in now, and what changes can I expect as his or her disease progresses?
- What treatments or activities are available to slow the progression of the disease? What if any medications might be helpful?
- Are there any Alzheimer's disease clinical trials that might be appropriate to consider?
- What community services and support organizations for Alzheimer's are available in my area?



QUICK TIP

If your employer offers an employee assistance program, it can help you problem solve and locate resources.

MANAGING THE DISEASE: BECOME INFORMED

One of the first steps following a diagnosis of Alzheimer's disease and other dementias is identifying your family's specific needs to determine what kind of help and support you may need. When considering how best to meet the needs of the person with dementia, it is important to think about what's best for the person while also evaluating the impact that caregiving is having on your own well-being.

As a caregiver, you may want to start by contacting one of the Alzheimer's organizations within our state to receive free, insightful information for the person diagnosed and to learn about the importance of taking care of your own medical, physical, and emotional health and well-being. Additionally, there are websites available that provide information useful to caregivers, provided on the checklist offered to you.



Caregiver Quick Guide

Initial Steps After Diagnosis

The Alzheimer's Association and Alzheimer's Tennessee offers free literature on all-things dementia, care consultation and navigation services, training and education, support groups, and local resources and referrals to people living with the disease, caregivers, and families. Some regional offices may conduct an in-home care consultation to help determine the best care options and assist you in navigating and securing services.

ALZHEIMER'S ASSOCIATION 24/7 HELPLINE (800.272.3900)

West TN Regional Office: Memphis,
901-565-0011
Middle TN Regional Office : Nashville,
615-315-5880
Southeast TN Regional Office: Chattanooga,
423-265-3600
East TN Regional Office: Knoxville,
865-200-6668
Northeast TN Regional Office Kingsport,
423-928-4080

ALZHEIMER'S TENNESSEE 888-326-9888 OR 24/7 HELPLINE 1-800-259-4283

East TN Office: Knoxville,
865-544-6288
Cumberland Office: Cookeville,
931-526-8010
Northeast TN Office: Johnson City,
423-232-8993
Middle TN Office: Nashville,
615-580-4244
South Central TN Office: Tullahoma,
931-434-2348
West TN Office: Jackson,
731-694-8065

ASSESSING YOUR NEEDS

Several federal government benefits programs and state services may help Alzheimer's patients and their family members identify and pay for support like medical care, home and community based services, disability, and respite care.

It may be useful to assess what your current and future needs may be to determine what kind of help and support will be required. A few areas to explore:

- What type of assistance is needed (bathing, walking, transferring, medication management, medical decision-making, financial oversight, supervision, meal preparation, transportation)?
- Will insurance cover any in-home or long-term care services outside of our home? If not, how much money is needed and do we have it available?
- Are there specific days and times that I will need assistance?
- What kind of assistance can I provide myself? What types of assistance are my family and friends willing to provide?
- Can we adjust to having others in our home to assist us?
- Can I navigate and secure the services myself? Who can I contact for assistance?



Caregiver Quick Guide

Initial Steps After Diagnosis

OPTIONS TO CONSIDER

INFORMAL CAREGIVING

informal care may consist of assistance from family, friends, and your faith-based community who have been identified as providing regular and sustained care and assistance to your loved one without expectations of being paid. Even with the help of others, providing care to a person with Alzheimer's disease can be overwhelming which is why you may want to consider including others in the caregiving role.

The impacts of caring are substantial and wide-ranging, and while many positive impacts have been reported by some, many caregivers experience negative effects on their emotional, psychological and physical health, social activities and support networks, ability to work and finances. Building this informal support team in advance of an emergency situation can help minimize stress and feelings of being overwhelmed.



QUICK TIP

When asking for assistance, be very specific and clearly share what help is needed now or in the future.

IDENTIFYING & SECURING COMMUNITY RESOURCES

The Tennessee Area Agencies on Aging and Disabilities (AAAD) are trusted sources of information and assistance, where older adults can turn to find specialized information, supports and service options in their area. They also offer Family Caregiver Support Programs that assist family members as they are helping a loved one with dementia or other conditions. Your local AAAD can provide general information about eldercare and referrals to aging-related services and programs in your community. Resources offered by the AAAD can include:

- Caregiver support
- Information and assistance
- Transportation
- Home-delivered meals
- Public Guardianship
- State Health Insurance Assistance Program
- Legal assistance
- Home and community based services
- Health promotion and prevention

Services listed above are not exhaustive and will vary between agencies. Eligibility criteria do apply and also vary. Contact the Tennessee Commission on Aging and Disability (TCAD) by calling 1-866-836-6678 to identify supports and services in your area for which you may be eligible.



Caregiver Quick Guide

Initial Steps After Diagnosis

TENNCARE CHOICES PROGRAM

Tennessee's CHOICES is part of TennCare Medicaid, the health care program paid for by the state and federal governments. The CHOICES program includes nursing facility services and home and community-based services (HCBS) for adults 21 years of age and older with a physical disability and seniors (age 65 and older). CHOICES offer services to help a person live in their own home or in the community.

To be eligible to receive CHOICES, you must meet income and property rules. You must also meet one set of the "level of care" rules which means how much care you need. One set of the new level of care rules is called the acuity scale or rules. Acuity means how serious or bad your health problems are, by how much and what kind of help you need with medical care. It also shows how much help you need with activities of daily living. Activities of daily living are things like walking, eating, going to the bathroom, etc. The other set of level of care rules is called the Safety Determination. To meet these safety rules, you must have proof that you and others around you cannot be safe in your home environment. If you meet the rules of either set, you meet the medical rules for that care group.



QUICK TIP

When contacting TCAD, ask to be assessed for the CHOICES program through an in-home assessment. If you have Alzheimer's disease and other dementias, ask for a safety determination to be performed.

How to apply? If you already have TennCare, contact your TennCare health plan to apply (The telephone number is on your TennCare card.) If you do not have TennCare, contact the Tennessee Commission on Aging and Disability (TCAD) by calling 1-866-836-6678.

VETERANS BENEFITS

The U.S. Department of Veterans Affairs offers numerous benefits to honorably discharged and qualified aged or disabled veterans including rehabilitative, residential and medical care and services. Veteran Service Officers can assist you in identifying benefits, help you complete and submit paperwork and file claims. You can call 888-777-4443 to receive assistance locating your local county Veteran Service Officer. Information about veteran's benefits may be found at: <https://www.va.gov/>.

The VA has extensive resources for caregivers of Veterans or Veterans who are caregivers. Check the website www.caregiver.va.gov to find out who your Caregiver Support Coordinator is. They can help connect you to resources for you as a caregiver. The Veteran must be receiving VA services.



Caregiver Quick Guide

Initial Steps After Diagnosis

ADULT DAY CARE & RESPITE CARE

Respite provides short-term relief to caregivers by offering a temporary reprieve from caregiving duties. Respite can be provided in the home, outside the home, at an adult day care program, in a hospital or facility setting such as a nursing home or an assisted living facility. Informal respite services can be provided by family or friends. Services may be free or offered on a sliding financial scale, provided through long-term care insurance, private insurance or our state's TennCare CHOICES program.

LEGAL & FINANCIAL SERVICES

These services are often needed when the diagnosed individual can no longer manage legal and/or financial affairs. As the disease progresses, you'll find yourself taking on more of their legal and financial responsibilities. In the early stages of the disease, the individual may be able to participate in legal and financial planning. Consideration should be made to identify and meet with an attorney that specializes in elder law to explore financial and health care decision making through the use of durable powers of attorney and end of life decision making through the completion of the advance directive for health care form. It is important to gather, at a minimum, the below documents as soon as possible to prepare for your loved one's future:

- Birth certificate and social security card
- Social security payment information
- Monthly or recurring bills
- Insurance policies
- Medicare or Medicaid cards
- Deeds, mortgages or statements of ownership
- Certificates for stocks and bonds
- Retirement benefit summaries and pensions
- Wills and trusts

The TN Senior Legal Helpline is a toll-free line (1-844-435-7486) offering legal assistance and advice for Tennesseans aged 60 or over.

Advance Directive for Health Care form tells your physicians, family and friends what type of medical care you do or do not want when you can no longer make these decisions on your own. The Advance Directive for Health Care form can be located on the Tennessee Department of Health website.

Model Form:

https://www.tn.gov/content/dam/tn/health/documents/Advance_Directive_for_Health_Care.pdf

Instructional Advance Directive video: https://youtu.be/kY_bUCIfaNE



Caregiver Quick Guide

Initial Steps After Diagnosis

HOME & COMMUNITY BASED SERVICES

Common types of in-home care services: non-medical personal support services, medical care provided through home health, palliative care or hospice services. Depending on the type of services, costs for home care services may be covered under Medicare, private insurance or through the TennCare CHOICES program.

HOME HEALTH

Home health provides skilled nursing care and therapy services to patients in their own residence. The patient must be under the care of a physician, meet the definition of "homebound," and be in need of skilled services on an intermittent basis. Services include care from a skilled nurse, physical therapists, occupational therapists, speech-language pathologists, and medical social workers. Home health aides provide personal care services for patients also in need of skilled services.

LONG DISTANCE CAREGIVING

Providing care to a loved one with Alzheimer's disease and other dementias who does not live near you can be challenging and stressful. Consider securing a geriatric care manager/ elder law attorney to assess and monitor the needs of your love one. During visits, attend medical appointments and establish a communication plan with care team, assess in-home safety and driving, medication management, personal appearance, etc.



QUICK TIP

If considering eligibility for home health services, discuss with the primary care physician the option of also receiving services from a licensed medical social worker to assist with identifying and navigating community resources.



CAREGIVER CHECKLIST

- I have asked the healthcare provider the following questions:**
 - What stage of Alzheimer's disease is he or she in now, and what changes can I expect as his or her disease progresses?
 - What treatments or activities are available to slow the progression of the disease? What if any a medications might be helpful?
 - Are there any Alzheimer's disease clinical trials that might be appropriate to consider?
 - What community services and support organizations for Alzheimer's are available in my area?

- I have contacted the Alzheimer's Association or Alzheimer's Tennessee to receive more information.**

- I have contacted the Tennessee Commission on Aging and Disability (1-866-836-6679) and have asked about the following resources:**
 - Caregiver support
 - Information and assistance
 - Transportation
 - Home-delivered meals
 - Public Guardianship
 - State Health Insurance Assistance Program
 - Legal assistance
 - Home and community based services
 - Health promotion and prevention

- I have gathered the following documents:**
 - Birth certificate and social security card
 - Social security payment information
 - Monthly or recurring bills
 - Insurance policies
 - Medicare or Medicaid cards
 - Deeds, mortgages or statements of ownership
 - Certificates for stocks and bonds
 - Retirement benefits summaries and pensions
 - Wills and trusts

- I have accessed my loved one's Advanced Directive or have begun discussing an Advanced Directive with my loved one.**

- I have contacted my personal lawyer or TN Senior Legal Helpline (1-844-435-7486).**

- My loved one is a veteran and I have contacted the Veteran's Affairs for the Veteran and for myself as a caregiver.. Call 888-777-4443 to locate your local county Veteran Service Officer.**

NOTES

HEALTHCARE PROVIDER

Name: _____

Title: _____

Date and time: _____

Additional Notes:

ALZHEIMER'S ASSOCIATION OR ALZHEIMER'S TENNESSEE

Name: _____

Title: _____

Date and time: _____

Additional Notes:

NOTES

TENNESSEE COMMISSION ON AGING AND DISABILITY

Name: _____

Title: _____

Date and time: _____

Additional Notes:

AREA AGENCY ON AGING AND DISABILITY

Name: _____

Title: _____

Date and time: _____

Additional Notes:

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LEGAL SERVICES

Name: _____

Title: _____

Date and time: _____

Additional Notes:

VETERANS AFFAIRS

Name: _____

Title: _____

Date and time: _____

Additional Notes:

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OTHER CONTACTS

Name: _____

Title: _____

Date and time: _____

Additional Notes:

Name: _____

Title: _____

Date and time: _____

Additional Notes:
