Caregiver Toolkit

The Caregiver Toolkit was developed to provide resources to caregivers. Click the links below for specific resources based on who you are caring for. *Note: The inclusion of non-AOTA items in this resource does not reflect endorsement by AOTA.*

- Caring for Yourself or Other Caregiver
  - Finding Local Resources
  - Caring for Yourself: Health and Wellness
  - Balancing Work and Caregiving
- Caring for a Child
  - General Information and Resources
  - Autism
  - Cerebral Palsy
  - Down Syndrome
  - Spina Bifida
- Caring for Adults and Older Adults
  - General Information and Resources
  - Aging in Place
  - Fall Prevention and Home Modification
  - Older Adults and Driving
  - Alzheimer’s Disease
  - Arthritis
  - Chronic Pain
  - Diabetes
  - Joint Replacement
  - Low Vision
  - Stroke
  - Rehabilitation and Disability
- End-of-Life Resources

*Caring for Yourself or Other Caregivers*

It may seem odd to have this be the first section of a caregiving toolkit. After all, you probably are looking for resources to help someone you’re caring for. But in order to do that, you need to take care of yourself as well. This is not being selfish. While caring for a loved one can be a rewarding and meaningful experience, caregivers can experience feelings of distress and burnout. Caregiving is a big responsibility. Many times, a caregiver will put his or her own needs aside when caring for a loved one. However, it is important for caregivers to care for themselves, continuing to pursue their own hobbies and daily activities, while taking care of a loved one.
This page has a number of resources that emphasize the importance of caregiver health and wellness. Additionally, this page looks into the many kinds of disruptions or illnesses an individual may face throughout his or her life, and provides fact sheets and websites that can be used as guiding resources.

**Finding Local Resources**

- **Rosalynn Carter Institute for Caregiving**
  - The Rosalynn Carter Institute has compiled a comprehensive list of useful tools and websites to help caregivers navigate through daily life issues with ease.

- **AARP Caregiving Checklists**
  - Multiple checklists that are beneficial to a caregiver. They include a home safety checklist; ways to prevent falls; ways to ask about and deal with pain; and what to ask when looking at various care facilities, including home health, nursing homes, and hospice.

- **VA Caregiver Toolkit Modules**
  - The family caregiver toolbox was created by the U.S. Department of Veterans Affairs and has links to information ranging from resources for new caregivers, to condition-specific care sheets, everyday tips and checklists, and much more.

- **Eldercare Locator**
  - This locator tool searches for adult day care and local resources for Alzheimer’s disease, caregivers, elder abuse prevention, financial assistance, food and nutrition, health insurance, healthy aging, home repair and modification, housing options, in-home services, legal assistance, long-term care, nursing home and long-term-care facilities, transportation, and volunteering.
  - The website provides fact sheets on adult day care, assisted living, assistive technology, and government-assisted housing, home health care, home modifications, hospice care, face the facts, 10 warning signs, a talk with an elder driver. Call for more information: 800-677-1116

- **Emergency Preparedness Checklist and Supplies to Have at Home.**
  - This checklist can make sure you and your loved ones are prepared in case of emergencies.

- **National Caregivers Library**
  - Resources on housing, money and insurance, physical and emotional health, planning and assessment, record keeping and legal matters, and end-of-life issues. All of the checklists and forms are written for caregivers to help them plan, make decisions and stay informed.

- **Respite Care**
  - The National Respite Locator Service helps parents, family caregivers, and professionals find respite services in their state and local area to match their specific needs.
Caring for Yourself: Health and Wellness

- **AARP Caregiver Resources**
  - Online tool that provides information on caregiver preparation, legal and financial considerations, how to provide care, caring for yourself, and much more.

- **AARP Free Caregiving E-Book**
  - 20-page guide book for caregiving with tips, cutout forms, and information on nurturing the caregiver
  - Available in English and Spanish

- **AOTA Health and Wellness Pinterest Page**
  - Information on various conditions, positive ways to cope with stress, creative solutions, and ways to keep yourself happy and healthy.

- **Caregiver’s Bill of Rights**
  - List of 10 “I have the right…” bulleted statements for caregivers.

- **Caregiver’s Pledge**
  - List of 10 statements for caregivers to help manage the stress and responsibility of caring for another.

- **Caregiver Resource Network**
  - Provides significant information and solutions to common caregiver health and wellness concerns such as anticipating the holidays, symptoms of depression in older adults, healthy living strategies, and much more.

- **Caregiving While Maintaining Your Health: Keys to Health and Wellness**
  - Tool for caregivers who are looking for ways to manage their health and wellness. Provides specific tips for staying physically, mentally, emotionally, socially, and spiritually well.

- **Family Caregiver Alliance—Caregiver Preparation**
  - Comprehensive website that focuses on specific situational concerns such as being new to caregiver, long distance caregiving, and steps to take post-caregiving.

- **Helping you Care: Caregiver Self-Care, Stress Management, & Survival Tips**
  - Tips and strategies for learning to care for yourself so that you can be the most effective caregiver for your loved one while still maintaining your own health and wellness.

- **“Taking Care of YOU: Self-Care for Family Caregivers”**
  - Information on the importance of taking care of oneself while caring for a significant other. The article discusses tips for reducing stress, setting goals, talking to physicians, and much more.

- **Preventing Injury to Yourself: Safe Lifting and Transfer Techniques for Caregivers**
  - This handout, created by Northwestern Memorial Hospital, provides ergonomic information on safe lifting and transfer techniques, including pictures. For
example, it addresses safe techniques when using a sheet to turn someone, and bed making when a sheet is soiled.

Balancing Work and Caregiving

- **AARP Caregiver Tips for Balancing Work and Caregiving**
  o Tips for caregivers to effectively cope with the stress of balancing multiple priorities that often accompanies taking care of loved ones. Provides strategies to help caregivers balance the many demands of work and home.

- **AARP Fact Sheet: Understanding the Impact of Family Caregiving on Work**
  o Provides information regarding the common concerns of caregivers in regard to their ability to work as well as explains policies that are in place to help caregivers in the workplace.

- **Balancing the Roles of Worker and Caregiver**
  o Provides three steps for working caregivers to effectively cope with stress and the ever-present demands on time, energy, and resources.

- **Tips for Balancing Career and Caregiving**
  o Addresses the challenges associated with working while caregiving. It touches on how your employer may be able to help you, how to avoid caregiver burnout, how to create a contingency plan, and many more topics.

Caring for a Child

This section provides a multitude of resources for caregivers of children and adolescents with autism spectrum disorders (ASD), cerebral palsy, and other developmental disabilities. Note that children with developmental disabilities may eventually have adult caregiver needs. Resources are available for grandparents and parents, as well as siblings.

General Information and Resources

- **AARP GrandFacts**
  o General and state-specific fact sheets for grandparents and other relatives raising children.
  o Information on state laws, education assistance, public benefits and financial assistance, foster care services, state and local resources, and census data.

- **My Child Without Limits**
  o Focused information on how to care for children with various physical and cognitive disabilities, including early intervention, family support services, common treatment options, and much more. Conditions include, but are not limited to, Down syndrome, muscular dystrophy, autism, and spina bifida.

- **Center for Parent Information and Resources**
Resources on Parent Training Information (PTI) Centers and Community Parent Resource Centers (CPRCs) serving families of children with disabilities in each state.

The article “The Unplanned Journey” provides information for caregivers of family members with a disability, including supportive information for parents, siblings, and grandparents.

It also includes links to informative resources regarding special education and related services information.

- **Sibling Support Project**
  - National program for brothers and sisters of those with “health, developmental, and mental health concerns.” Helps communities establish local “Sibshops,” which are peer support groups.

**Diagnosis-Specific Resources**

**Autism**

- **Autism Speaks**
  - The Resource Guide section includes information on travel tips, summer camps, IEP resource guides, and more
  - Tool Kits provide information for families regarding behavioral and medical treatment and a variety of topics including toilet training, dental care, employment, sleep, and family support.

- **Caregiver Community**
  - An online community where caregivers caring for individuals with autism can connect with one another, provide support and guidance, and share ideas and resources. Other resources available are activity handouts and recommended books for understanding autism and coping with caregiving.

- **Caregiver’s Workbook**
  - For those caring with children, adolescents, and adults with autism. Contains handouts, quizzes, and exercises that touch upon the emotional components of caregiving, how to remain engaged in social circles, and how to manage your daily routine while caring for your loved one.

**Cerebral Palsy**

- **Care Guide: Medical Information**
  - Doctor appointments, medications, milestones, medical histories, and more are difficult to keep track of. The Cerebral Palsy Family Network created the Care Guide to help you organize and track this important information so you can easily share it with your child’s caregivers, therapists, and medical providers.

- **My Child Without Limits: Cerebral Palsy**
This is a comprehensive resource for parents and caregivers to learn more about their child’s diagnosis, the common treatment options that families seek, and how to locate local resources that can improve your child’s life.

- **United Cerebral Palsy**
  - Parents and Families section provides family support resources and helpful information for caregivers of children with disabilities.

### Down Syndrome

- **National Association for Down Syndrome**
  - The National Association for Down Syndrome provides helpful tips and strategies to combat feelings of burnout, along with basic diagnosis information, local support groups, resources for siblings, and skill development information. It has also created a [caregiver survey](#) to evaluate quality of life and stress level, to give caregivers a voice and add to the research to support future change.

- **My Child Without Limits: Down Syndrome**
  - Provides information about the causes and progression of Down Syndrome and how it affects physical, cognitive, and social functioning. Includes information regarding common health problems and many more resources to help caregivers gain a greater understanding of their child’s diagnosis.

- **National Down Syndrome Society**
  - Resources for caregivers include local support, treatment programs, education, caring for your family, and transition services.

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### Caring for Adults and Older Adults

Caring for an adult or older adult can be difficult and may result in many lifestyle changes, not only for the individual, but for the caregiver as well. The kind of care that adults and older adults need varies greatly—from managing physical and cognitive changes as a result of disability or illness, to managing medications and doctor appointments. Caregivers often experience a feeling of being overwhelmed; however, many find great reward in taking care of their loved ones. These resources will help guide your journey as a caregiver to an adult or older adult and provide information regarding lifestyle changes that can improve overall quality of life.

#### General Information and Resources

- **Economic Security**
  - National Council on Aging resource to help access benefits, explore their home equity options, find jobs and training, and better manage their money.

- **LongTermCare.gov**
Explains long-term-care services and costs, including what is and is not covered through Medicare and Medicaid. Provides local, state, and national costs and estimated future costs.

- **Understanding Medicare**
  - Information specific to your state and areas of interest, along with links to other websites.
  - [Find a Nursing Home](#) rates nursing homes by ZIP code or nursing home name.
  - [Find a Home Health Agency](#) rates home health agencies by ZIP code or agency name.

**Aging in Place**

- **Financial Planner**
  - This website addresses locating benefits, questions to ask an elder law attorney, a glossary of financial terms, financial planning calculators, sources for financial and legal information and assistance, locating free or subsidized health care services and prescription medications, and a checklist for important legal and financial documents.

- **Helping Your Older Parents Remain at Home**
  - Tip sheet for caregiver and how to help family and friends age in place safely in their own home and how occupational therapy can assist in this process.

- **National Family Caregiver Support Program**
  - The Administration for Community Living through the U.S. Department of Health and Human Services has information on the National Family Caregiver Support Program. This program helps fund support for the family and informal caregivers to help keep their loved one at home for as long as possible. It has additional links on the bottom of the webpage for its national caregiving and locator partner websites.

- **Organize Important Documents and Phone Numbers**
  - This AARP resource helps you organize phone numbers of doctors, lawyers, banks, etc. It can also help organize information regarding insurance, finances, medical documents, and information on the person’s final wishes.

- **Personal Medication Record**
  - This AARP resource helps to organize personal information, doctor contact information, allergies, medical conditions, and other medication information.

- **Remaining in Your Home as You Age**
  - Tips on how to stay as safe as independent in your home as possible. Also available in [Spanish](#) and [large print](#).

**Home Modification**

- **AARP Home Fit**
Article discusses how an occupational therapist or a certified aging in place specialist (CAPS) can assist in modifying your home to maximize safety and ease of use.

A video at the bottom of the main webpage provides more information on what home modifications are and a quiz to determine whether your home is aging friendly.

- **Caregiver’s Guide to Creating a Safe Environment**
  - Helps identify danger zones, respite zones, and safe zones in the home. Includes tips for simple modifications that are organized by room.
- **Video on Occupational Therapy in Home Modification**
  - Shows how occupational therapy can help people stay in their homes despite illness or disability.

**Fall Prevention**

- **Fall Prevention for Older Adults**
  - AOTA tip sheet on how to reduce the risk of falling by addressing lighting, clutter, and other safety issues. Also available in large print.
- **Older Adult Falls**
  - Centers for Disease Control and Prevention facts about falls, along with resources on how to prevent them.
- **Preventing Falls: Tips for Older Adults and Caregivers**
  - National Council on Aging resources, including falls prevention success stories, ways to prevent a fall, and debunked myths about older adults and falls.
- **Video on How To Reduce Falls**

**Driving**

- **AAA Senior Driving**
  - Links to self-rate driving ability quickly online as well as information regarding driving improvement courses for older adults and how medications can affect driving abilities.
- **Car-Fit**
  - CarFit is a program for older adults to ensure that their personal vehicles properly “fit” them. The website provides links to locate a CarFit event near you, as well as educational videos on how to properly adjust various items in the car.
- **Driving and Community Mobility FAQs**
  - Common questions about driving rehabilitation services and how to get started.
- **Driving Resources for Clients**
  - Where to start if you’re concerned, common age-related changes affecting driving, and what occupational therapy can offer, and more.
- **Find a Driving Specialist**
  - Search AOTA’s nationwide database of driving programs and driver rehabilitation specialists. An occupational therapy specialist can recommend ways
to limit risks if needed, or find other ways to keep the person mobile in the community.

- **Keeping Older Drivers Safe**
  - Offers caregivers of older adults ways to approach the topic of safe driving and next steps, along with how an occupational therapist can support this process and provide options.

- **Driving Safely as You Age**
  - Tips on how to be as safe as possible on the road. Also available in [Spanish]( ).

- **Safe Driving Tips for Seniors**
  - Brochure offering 5 tips, along with ways an occupational therapist can help keep drivers safe.

- **Tips for Driving Safely**
  - Recommendations on how to drive safely, along with suggestions for other ways to get around in the community.
  - Discusses how an occupational therapist can offer additional services, such as providing a comprehensive driving evaluation.

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**Diagnosis-Specific Resources**

**Alzheimer’s Disease and Dementia**

- **Alzheimer’s Behavior Management**
  - Tips for managing common symptoms and problems in people with dementia.
  - As a caregiver for a loved one with Alzheimer’s disease or dementia, it can be extremely worrying to experience behavior problems such as wandering, aggressiveness, hallucinations, or sleeping and eating difficulties. By learning how to make changes in the caring atmosphere, you can increase the quality of life for both the individual and yourself.

- **ALZ Connected**
  - A resource for both caregivers and those who are diagnosed with dementia to communicate with others through free forums on the website regarding safety, care, and tips for daily life activities. The caregivers allows users to express their concerns, ask questions, and provide support.

- **Caregiver Toolkit Modules**
  - The family caregiver toolbox is for caregivers of people with dementia, but the resources are useful for others as well. It has modules on financial planning (locating benefits, locating food assistance, questions to ask an elder law attorney), respite care, maintaining an up-to-date medication list, an incontinence assessment to help you get the best resources, bereavement services, how to find a support group, and many others.
• **Unpredictable Behaviors of Dementia**
  - Brochure from the Alzheimer’s Association on common dementia-related behaviors and how to appropriately respond.

• **C-TIPS: Customized Toolkits of Information and Practical Solutions**
  - A resource for caregivers to explore leisure activities and other activities with individuals with Alzheimer’s disease or dementia.
  - Allows you to choose an activity, then it is analyzed for estimated cost and potential modifications to make it easier or more challenging.

• **Living with Alzheimer’s Disease**
  - Tip sheet offering ideas for promoting quality of life while maintaining safety for the person with Alzheimer’s disease, and how occupational therapy can help.

• **Medication Safety and Alzheimer’s**
  - Resource by the Alzheimer’s Association that provides useful tips on how to coordinate physicians, avoid drug interactions, and ensure that medications are taken as directed.

• **Stages of Alzheimer’s Disease and the Changing Roles of the Caregiver**
  - The Family Caregiver Alliance provides an in-depth description of the various stages of Alzheimer’s disease, and the caregiver’s role during those stages.
  - Links include caregiver education, policy and advocacy, personal caregiver stories, and access to support groups.

**Arthritis**

• **Arthritis Foundation**
  - Information about arthritis, including tracking tools, a drug guide, Q and As, an online community, and additional resources.

• **Tip Sheet for Living With Arthritis**
  - Ways to maximize function, increase energy, and reduce pain, along with how occupational therapy can help.

**Chronic Pain**

• **Pain Management Tools**
  - Resource by the American Chronic Pain Association provides free, easy-to-use guides on ways to manage pain, stay engaged in life, and cope with the experience of pain itself. Provides users with visual tools to help track and monitor pain symptoms to better communicate with health care providers.

• **Caregiver Corner: Partner’s Against Pain**
  - Provides caregivers with useful tools and guides to help monitor and manage the pain of their loved ones. Resources include learning more about pain experienced by older adults, how to assess pain in loved ones with dementia, and how to advocate for your loved one.

**Diabetes**

• **Diabetes Life: Friends and Family**
Many resources for caregivers related to understanding diabetes, managing symptoms, building healthy lifestyles, including the whole family in care, and effectively talking to health care professionals.

**Joint Replacement**
- **Daily Activities After a Hip Replacement**
  - Resource providing information on how occupational therapy can be a valuable service for individuals who have had a recent hip replacement
- **Hip Precaution Visual Reminder**
  - 7-page printout provides visual reminders for basic hip precautions that need to be maintained during the weeks following surgery
  - Precautions will be specific to each patient, so always follow your physician’s recommendations
- **Total Knee Replacement: Before, During, and After**
  - Information regarding what a total knee replacement is, what to do before surgery, what surgery will consist of, and how to manage daily life after a total knee replacement. Includes the do’s and don’ts to follow after surgery as well as helpful tips on how to complete daily activities.

**Low Vision**
- **Living With Low Vision**
  - Recommendations to increase function, safety, and independence in the home for those with low vision
- **Vision Aware: Everyday Living With Low Vision**
  - Resource for both individuals with low vision and their caregivers. Includes tips and strategies to increase independence in the home, at work, and in the community.

**Recovering From Stroke**
- **Recovering From Stroke**
  - Offers ways to increase safety, independence, and function. Includes occupational therapy interventions such as one-handed dressing techniques, exercise programs, and home and work evaluations.
- **Aphasia Apps**
  - Communication can become difficult after a stroke, which puts extra strain on caregivers. This resource provides information on useful and inexpensive apps that can be downloaded to phones and other platforms to help your loved ones communicate more easily.
- **Caring for a Stroke Survivor**
  - The American Heart Association and the American Stroke Association have put together a comprehensive resources for those caring for a stroke survivor. They include practical tips, daily home care, and resources for day-to-day success.
- **Family Caregiver Alliance: Caregivers of Stroke Survivors**
The Family Caregiver Alliance and the National Center on Caregiving have created a resource specifically for caregivers of stroke survivors. Resources and additional information can be found towards the bottom of the main page.

- **Veterans and Stroke Survivors**
  - The U.S. Department of Veterans Affairs has developed 44 fact sheets with information that includes emotional and behavioral needs, obtaining good health care and information, and how to locate community resources.

### Rehabilitation and Disability

- **Able Data Website—Assistive Technology**
  - A user-friendly database for assistive technology, with products organized by type. There is a resource list for further information on assistive technology and how to acquire it.

- **Energy Conservation**
  - Tips for caregivers as well as loved ones to have the energy for the things you want and need to do.

- **Questions to Ask Your Doctor**
  - Helpful tips regarding the right questions to ask your doctor during your next visit. Use this information as a way to get high-quality health care information and take on an active role in all decisions made about your loved one’s care.

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### End-of-Life Resources

Being a caregiver during an end-of-life period can be difficult, yet rewarding. Although dying is a natural part of life, it can come with a variety of emotional challenges. Caregivers often experience mixed emotions, shifting between loss, grief, acceptance, and relief. These resources are here to help guide you through this transition and address the common experience of death and dying, how to manage emotions, how to avoid burnout, and how to maintain a strong and healthy relationship with your loved one.

- **AARP Guide to End of Life Care**
  - A variety of resources for caregivers on how to plan for end-of-life care, how to talk with family members about end-of-life decisions, and how to find comfort through the dying process.

- **ABCs of Respite Care: A Guide for Family Caregivers**
  - Information about the different types of respite, how to find services in your community, and how to select a quality respite provider.

- **End-of-Life Caregiving Information Booklet**
- Information regarding the natural progression of death and what changes you may see. Provides tips on how to improve the quality of life for both you and your loved one.
- **Family Caregiver’s Guide to Hospice and Palliative Care**
  - Addresses when to think about hospice, who decides if your family member can’t make a choice, services included, who pays, how to choose, what happens once it begins, and differences between palliative care and hospice care.
- **Respite Care Network**
  - The National Respite Locator Service finds services in your state and local area to match your specific needs.

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