



## Eastern Pennsylvania – Delaware Geriatric Education Center (EPaD GEC)

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### **Alzheimer’s Disease Toolkit**

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## **Introduction and Toolkit Navigation**

Hello and welcome to the EPaD GEC Alzheimer's Disease Toolkit.

This toolkit contains resources for providers, clinicians, consumers, and caregivers. It is designed to assist you in accessing current information, as well as recommended tools, resources and identified best practices of care specific to Alzheimer's Disease for older adults.

The toolkit can be utilized as a standalone resource and as a parallel supplement to our online educational materials accessible on our website in the Education Section under the [Dementia Tab](#).

You are encouraged to review the educational materials to receive the fullest benefit from the toolkit.

The toolkit is divided into sections and addresses the areas outlined in the educational materials. You will find resources that include an array of useful information pertaining to Alzheimer's Disease.

## Top 12 Helpful Alzheimer's Disease Websites

Below you will find 12 helpful Alzheimer's Disease websites that touch on an array of services information, research and educational opportunities.

1. [Alzheimer's Association](#) website provides a multitude of information including current research, basic information about the disease, caregiver tips, events to be a part of, and other resources.
2. [Alzheimer's Foundation of America](#) website provides information about Alzheimer's Disease. Information provided includes a basic education of the disease, an introduction to caregiving, tips to home safety, and ways to connect to social workers.
3. [Alzheimer Research Forum](#) website is geared towards current and past research studies conducted on Alzheimer's disease.
4. [American Health Assistance Foundation Alzheimer's Disease Research](#) webpage has a wealth of information around Alzheimer's Disease to include treatment, living with the disease, a link to ask an expert, and current research grants.
5. [Emory University Alzheimer's Disease Research Center\(ADRC\)](#) website focuses on the findings of the ADRC at Emory University along with information about healthy aging, dementia, family life, and various news and events.
6. [Mayo Clinic](#) website's section on Alzheimer's Disease includes links to various areas of interest such as symptoms, causes, risk factors, complications, ways to prepare for doctor's appointment, tests and diagnosis.
7. [National Alliance for Caregiving](#) website has various resources and educational information to support caregivers caring for loved ones with Alzheimer's disease.
8. [National Council of Certified Dementia Practitioners](#) website contains educational resources to include PowerPoint presentations and toolkits to support in-service training for staff, family, volunteers and congregation.
9. [National Institute on Aging Alzheimer's Disease Education and Referral Center](#) website includes education about the disease, how to find help; topics include caregiving, diagnosis, legal and research links to various Alzheimer's Disease Research Centers are provided as well as federal initiatives.
10. [National Institute on Aging Alzheimer's Disease Research Centers](#) website contains links and resources to Alzheimer's Disease Research Centers around the country.
11. [Penn Memory Center](#) a local Alzheimer's Disease Center's website contains resources on Alzheimer's disease to include but not limited to clinical studies, training opportunities, support group information.
12. [University of Pittsburgh Alzheimer's Disease Research Center](#) website contains information about Alzheimer's disease, caregiving, clinical trials, and memory evaluations.

## Websites for Caregivers

Below you will find 19 Alzheimer's Disease caregiver websites that touch on an array of services, support and educational opportunities.

1. [AARP Caregiving Resource Center](#) website provides users with various caregiving information it is not specific to Alzheimer's disease. Information provided includes a care provider locator, tips from experts, caregiving chat, caregiving message boards, care for the caregiver, and legal and financial matters.
2. [AARP: Find the Right Care for Your Loved One](#) website provides caregivers with different care options. Topics discussed include home health, assisted living facilities, nursing homes, hospice, and adult day care. Finding the right care for a loved one can be done by searching for care providers by zip code and by type of care.
3. [AARP Help for Alzheimer's Caregivers](#) website provides videos and essays for the user. Video and essay topics include: When A Caregiver Can No Longer Cope; The High Costs of Caring for Alzheimer's Patients; and How My Husband and I Dealt with Alzheimer's.
4. [AgingPro](#) website is divided into a number of categories to support caregivers, professionals in aging, planning for the patient's future and includes an eldercare directory.
5. [Alzheimer's and Dementia Caregiver Center](#) website contains a multitude of information including daily care ways to enhance daily life, the various stages of Alzheimer's Disease is covered and the behaviors associated with each stage, ways to get support, safety concerns, care options, and financial and legal planning. An Alzheimer's navigator, caregiver notebook, caregiver stress check, care training, and care team calendar are available on the website. The website has a section on top safety concerns, safety systems, special situations. It also offers a variety of care options and types of care; these include adult day centers, in-home care, residential care, respite care, and hospice care.
6. [Alzheimer's Caregiver Resource](#) website provides a vast amount of resources for caregivers of individuals with Alzheimer's disease. The website includes caregiving aids, products and videos that would be helpful for those affected by Alzheimer's Disease.
7. [Alzheimers.gov](#) website is a helpful resource for caregivers and provides local resources and counseling support.
8. [American Bar Association \(ABA\) Commission on Law and Aging](#) pdf document contains a toolkit from the American Bar Association about how to prepare health care advance planning. The toolkit contains 10 tools on several planning topics. Tools include topics like Are Some Conditions Worse than Death?, How Do You Weigh Odds of Survival? And After Death Decisions To Think About Now.
9. [Caring Connections](#) website contains information on caring for someone with an illness and planning ahead for that person. Information provided also includes living with an illness, the campaign LIVE without pain, and grieving a loss. This website also contains a wealth of information about advance directives such as What Are Advance Directives?,

- Healthcare Agents: Choosing One and Being One, Preparing Your Advance Directives, Storing Your Advance Directives, and How to Download Your State's Advance Directives. The website also has a section on Caring for the Caregiver which includes information around acknowledging the caregiver needs, assistance and taking breaks.
10. [Caregiving Help](#) website provides useful information for caregivers. The website provides information for caregivers interested in hiring a consultant. In addition, the website provides a good amount of information on caregiving, different perspectives, and planning ahead. It also has a section on home safety, fall prevention, medication management, and lifting and transferring.
  11. [Children of Aging Parents \(CAPS\)](#) CAPS is a website tailored to adults who are caring for their aging parents. The site includes CAPS support groups in different states, a "caregiver guide," helpful links, a newsletter, and special programs. CAPS is affiliated with Contact Greater Philadelphia. CAPS has also partnered with The Caregivers Advisory Panel (TCAP) to create mutual value and research in improving the lives of family caregivers.
  12. [Dementia Caregiver Resources, Inc.](#) website has a strong interest in reaching out to caregivers of individuals with dementia. The website provides a multitude of caregiver information including books, videos, newsletters, support groups, resource links, and special events.
  13. [Family Caregiver Alliance](#) website is devoted to providing copious amounts of information for caregivers of individuals with Alzheimer's, Parkinson's, TBI, and strokes. The website contains legal information, especially for those living in California. It also includes public policy and research, caregiving information and advice, fact sheets and publications, and newsletters.
  14. [Mayo Clinic](#) website's section on caregivers provides information about helping caregivers of patients with Alzheimer's disease. The website provides simple tips that caregivers can use.
  15. [National Institute on Aging: Caring for a Person with Alzheimer's Disease](#) website provides a 104 page handbook on caring for a person with Alzheimer's disease. "It addresses all aspects of care, from bathing and eating to visiting the doctor and getting respite care." The handbook is available online to the public. Additional discussion topics include planning ahead, keeping the person with Alzheimer's Disease safe, and helping family members and others understand Alzheimer's Disease.
  16. [National Institute on Aging Home Safety for People with Alzheimer's Disease Booklet](#) contains general safety concerns, home safety room by room, home safety behavior by behavior, impairment of the senses, driving, natural disaster safety, and other topics.
  17. [National Institute on Aging Legal and Financial Issues for People with Alzheimer's Disease A Resource List](#) website provides a comprehensive list of legal and financial issues that families and individuals with Alzheimer's disease will eventually face. Very practical, helpful website link. Provides an overview of helpful brochures, handbooks, toolkits, and other materials to help people with AD and their families make appropriate decisions.
  18. [NIH Senior Health](#) website designed by an occupational therapist contains information that is different from most other Alzheimer's disease websites. The information is broken down into daily activity categories such as personal care, residential care, home safety,

driving, caregiver support, and medication. On each page, tips and videos are provided to help the caregiver.

19. [Well Spouse Association \(WSA\)](#) website is aimed at bringing together spouses or partners of individuals who are chronically ill or disabled. The site's purpose is to remind the caregiver that he or she is not alone. Through stories, quotes, various resources, and support groups, the website does just that. Volunteer opportunities are also available on the website.

## **Screening Assessments and Clinical Tools**

Below you will find a few websites that link to screening assessments and clinical tools for Alzheimer's Disease.

1. [Alzheimer's Association Conducting an Assessment](#) website provides a comprehensive list of assessment tools. A few assessments include cognitive, functional, global and caregiver based assessments. Other helpful assessment tools that can be found on the Alzheimer's Association website include Tools for Early Identification, Assessment and Treatment for People with Alzheimer's Disease and Dementia, Chronic Care Networks for Alzheimer's Disease initiative.
2. [Geriatric Education Center of Greater Philadelphia Dementia in Hospice Care by Amy Corcoran, MD](#) The slide set discusses stages, guidelines and assessments to address pain and comfort.

## **Home Modification**

Below you will find a home safety and modification website to support safety in the home for the older adult.

1. [Caring Home A Project of Weill Cornell Medical College](#) website contains tips and tools to enhance home safety for persons with Alzheimer's and other types of dementia. Divides home into sections to "explore research-based solutions and home safety and daily care issues." A few content areas discussed on the home safety website includes
  - A. Bathroom tips to reduce risk of tripping and or falling.
  - B. Bedroom tips regarding lighting, addressing sleep issues, wandering and dressing
  - C. Kitchen and Dining tips on meal preparation, proper kitchen organizing and lighting.
  - D. Living room tips on proper furniture, flooring, lightning and tables.

## Other Caregiving Resources

Below are caregiving resources which provide tips, connections with fellow caregivers and education on taking care of their health.

1. [Alzheimer's Association Online Community](#) has message boards, chat rooms and an online communication forum. Individuals can share thoughts and experiences, ask colleagues, and make friends.
2. [American Medical Association Caregiver Assessment Tool](#) helps caregivers analyze their own behavior and health risks with a physician's help. Together they make decisions to benefit both the caregiver and the patient. Physicians identify and provide preventative services to an at-risk but hidden population and improve communication and enhance physician-family caregiver health partnership.
3. [National Institute of Health Caregiver Guide Tips for Caregivers of People with Alzheimer's Disease](#) this guide provides tips for caregivers providing care for people with Alzheimer's Disease.

## Support Groups

Below are Alzheimer's disease support group websites.

1. [Alzheimer's Association Support Groups](#) can search for support groups by zip code or by state.
2. [AlzOnline Alzheimer's Caregiver Support Online](#) provides resources and educational information for caregivers.

## Safety Services

Below are Alzheimer's Disease safety services websites.

1. [MedicAlert & Alzheimer's Association Safe Return](#) is a 24 hour nationwide emergency response service for individuals with Alzheimer's or related dementia that wander or have a medical emergency. It provides 24 hour nationwide assistance, no matter when or where the person is reported missing.
2. [Alzheimer's Association Comfort Zone](#) a web based location management service. Families can remotely monitor a person with Alzheimer's by receiving automated alerts throughout the day and night when a person has traveled beyond a present zone.
3. [Wristband- Cellular Network and 911 system](#) web page discusses the use of the wristband cellular network system to find missing persons.
4. [Watch Like Emergency Locator System](#) web page discusses the use of the watch like emergency locator system to find missing persons.