



Online Caregiving Resources

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WEBHEALTH TOPICS

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Online Caregiving Resources

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Caregiving the chronically ill, elderly, or disabled is challenging. The number of caregivers in the United States continues to rise. Many caregivers turn to electronic resources for assistance and support. Online, caregivers can access high-quality resources designed to address day-to-day, practical needs as well as help soothe the emotional, mental, physical, and spiritual stress brought on by caregiving. Some sites address general caregiving audiences while others are designed for specific types of caregivers or patient populations. Several sites provide information on assistive technologies or offer video “how-to” clips or documentaries featuring caregivers and their loved ones. If caregivers know where to look, information exists to meet every need.

KEYWORDS *Caregivers, caregiving, Internet, online resources*

INTRODUCTION

Caregiving of the chronically ill, elderly, or disabled is physically, mentally, spiritually, and emotionally challenging. The number of caregivers in the United States is rising. According to a 2013 Pew Internet Report, 39% of

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Americans (four out of every ten), aged 18 and older, currently care for an adult or child with significant health issues (Fox 2013). The National Alliance for Caregiving and United Hospital Fund conservatively estimate that an additional 1.4 million children aged 18 and below, provide care for family members who are unable to manage life independently (NACUHF 2005). The number of caregivers continues to increase as the baby boomer generation ages.

Not only does the burden of caregiving create personal stress and hardship for the individuals caring for friends, family, or clients; it also has a significant impact on the U.S. economy. A Gallup poll estimates that, due to caregiving duties, nearly one-third of working caregivers miss an average of 6.6 days of work per year (totaling an astounding 126,222,624 lost work days) and equaling \$25.2 billion of lost productivity (Witters 2011). These figures do not take into account the hours that students and children under the age of 18 engage in caretaking, sometimes at the expense of their studies.

Caregivers, their employers, local, state and federal governments, and numerous nonprofit organizations recognize the significant impact caregiving has on American society. Many of these entities have created programs, resources, and information to assist caregivers. Between working, caring for their families, and performing caregiving duties for aging parents, the chronically ill, or disabled, when do caregivers have the *time* to seek out support and helpful information?

More and more caregivers are turning to electronic resources easily accessible from home computers or mobile devices. Once online, caregivers have access to many high-quality resources designed to address day-to-day, practical needs as well as help soothe the emotional, physical, and spiritual stress brought on by caregiving duties. Some caregiving sites address general caregiving audiences, while others are designed for specific types of caregivers or specific patient populations. Still other sites provide information on assistive technologies or offer video “how-to” clips or documentaries featuring caregivers and their loved ones. If caregivers know where to look, there truly is something available to meet their every need.

GENERAL CAREGIVING

AARP Caregiving Resource Center

<<http://www.aarp.org/home-family/caregiving/>>

AARP, formerly known as the American Association of Retired Persons, provides an online list of helpful caregiving information. The Caregiving Resource Center contains a wealth of information, tools, and tips for caregivers.

American Academy of Home Care Medicine

<<http://www.aahcm.org/>>

The American Academy of Home Care Medicine (formerly the American Academy of Home Care Physicians) seeks to promote the art, science, and practice of medicine in the home. The association offers a directory of home care physicians, physician assistants, and nurse practitioners by state.

Caregiver Action Network (CAN)

<<http://caregiveraction.org/>>

CAN (formerly the National Family Caregivers Association) is a nonprofit organization providing education, peer support, and resources to family caregivers across the country free of charge.

The Caregiver's Handbook

<<http://www.acsu.buffalo.edu/~drstall/hndbk0.html>>

The Caregiver's Handbook provides a complete online guide for caregivers of the elderly. It is often recommended for people taking care of Alzheimer's patients, but it can also be useful for other types of caregiving.

Centers for Disease Control and Prevention—CDC's Healthy Aging

<<http://www.cdc.gov/aging/>>

The CDC's Healthy Aging site provides up-to-date, practical information for health professionals as well as for health consumers and caregivers.

Family Caregiver Alliance (FCA)

<<http://www.caregiver.org/>>

FCA represents caregivers, describing their daily challenges, offering assistance, and supporting education, services, research, and advocacy (Figure 1).

Family Caregivers Are Wired For Health

<<http://pewinternet.org/Reports/2013/Family-Caregivers.aspx>>

This report from the Pew Internet & American Life Project reviews the latest statistics about how family caregivers utilize online resources.

Home Safety Council (Safe Kids Worldwide)

<<http://www.safekids.org/>>

The Home Safety Council, a 501(c)(3) charitable organization, merged with Safe Kids Worldwide in 2011. The merger builds on the more than 40 years



FIGURE 1 Family Caregiver Alliance (FCA) Web page. © [Family Caregiver Alliance]. Reproduced by permission of Andrea Orvik, Communications Coordinator, FCA. Permission to reuse must be obtained from the rightsholder.

of combined experience of the two organizations in providing education and advocacy for preventing unintentional injuries. Under the Safe Kids Worldwide name, the organization is solely dedicated to the prevention of accidental injuries to children and adults of all ages.

MEDLINEplus National Library of Medicine: Caregivers

<<http://www.nlm.nih.gov/medlineplus/caregivers.html>>

MEDLINEplus is the highly respected consumer health information resource from the National Institutes of Health. Search “caregiver” for information on developing caregiver coping skills, research, specific medical conditions, law and policy, organizations, statistics, and specific populations.

National Alliance for Caregiving (NAC)

<<http://www.caregiving.org/>>

The NAC is a nonprofit coalition of national organizations created to conduct research, analyze policies pertaining to caregiving, develop national programs, increase public awareness of family caregiving issues, work to strengthen state and local caregiving coalitions, and represent the U.S.

caregiving community internationally. NAC provides extensive links to caregiving statistics and resources.

National Association of Professional Geriatric Care Managers (NAPGCM)

<<http://www.caremanager.org/>>

The NAPGCM is a nonprofit professional development organization committed to advancing professional geriatric care management through education, collaboration, and leadership. The site has a list of consumer videos and factsheets representing a variety of caregiver concerns.

National Association of Senior Move Managers

<<http://www.nasmm.org/>>

The National Association of Senior Move Managers is a 501(c)(6), not-for-profit, professional association of organizations that are dedicated to assisting older adults and their families with the physical and emotional demands of downsizing, relocating, or modifying their homes.

National Family Caregiver Support Program

<http://www.aoa.gov/aoaroot/aoa_programs/hcltc/caregiver/index.aspx>

The National Family Caregiver Support Program is a part of the Administration on Aging in the U.S. Department of Health and Human Services (HHS). Its Web site provides useful caregiving information.

Patient Advocate Foundation (PAF)

<<http://www.patientadvocate.org/>>

The PAF supports patients with chronic, debilitating, and life-threatening illnesses. The Foundation provides patient mediation and arbitration services to remove health care obstacles, such as medical debt crisis, insurance access issues, and employment issues. PAF offers a Co-Pay Relief Program at <www.copays.org>.

Rosalynn Carter Institute for Caregiving

<<http://www.rosalynncarter.org/>>

This service unit of Georgia Southwestern State University supports family and professional caregivers through advocacy, education, research, and service. The site has extensive, annotated, online resources for all types of caregivers.

USA.gov—Senior Citizens' Resources

<<http://www.usa.gov/Topics/Seniors.shtml>>

USA.gov shares resources for seniors on caretaking, money, housing, health, consumer protection, and more.

CAREGIVING POPULATIONS**American Association of Caregiving Youth (AACY)**

<<http://www.aacy.org/>>

This Florida-based 501(c)(3) nonprofit corporation addresses the issues of the more than 1.4 million children who provide care for family members unable to manage life independently due to illness, injury, disability, or advanced age.

Family Caregiver Alliance—Handbook for Long-Distance Caregivers

<<https://caregiver.org/handbook-long-distance-caregivers>>

This free PDF download is provided by the Family Caregiver Alliance. It describes how to assess a care situation, develop a care team, hold a family meeting, access community organizations and private agencies, and balance work and caregiving.

USA.gov—Grandparents Raising Grandchildren

<<http://www.usa.gov/Topics/Grandparents.shtml>>

USA.gov provides information designed to help grandparents raising grandchildren locate state grandparent programs and other information about benefits, assistance, and more (Figure 2).

National Association for the Education of Young Children—NAEYC for Families

<<http://families.naeyc.org/>>

The National Association for the Education of Young Children (NAEYC) supports quality early childhood education for children from birth through age eight. This site provides research-based tips and ideas on children's learning and development that families can trust.

Well Spouse Association

<<http://www.wellspouse.org/>>

The Well Spouse[®] Association, a nonprofit 501(c)(3) membership organization, advocates for and addresses the needs of individuals caring for a chronically ill

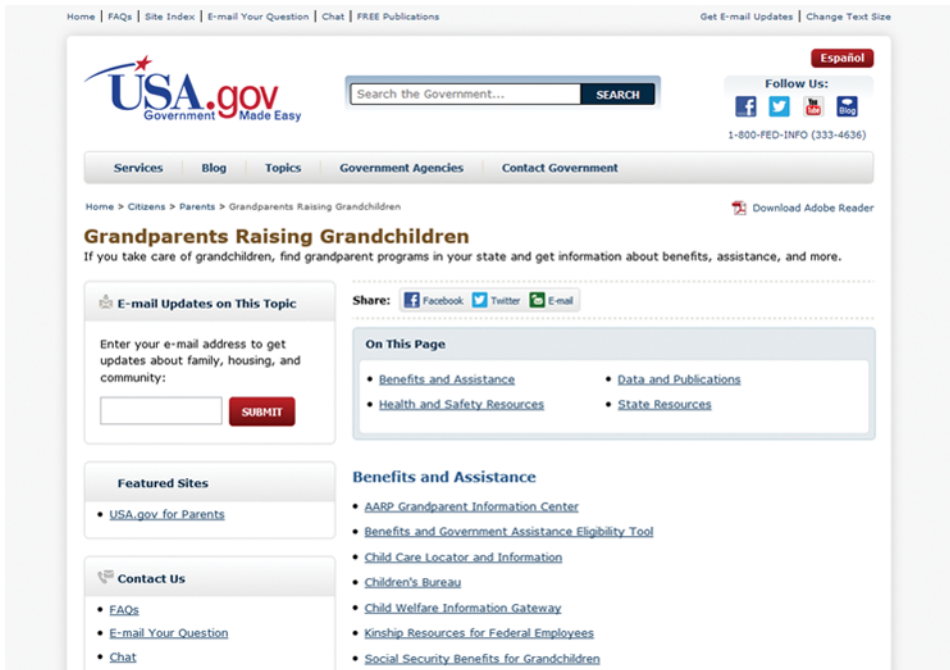


FIGURE 2 Grandparents Raising Grandchildren USA.gov Web page.

or disabled spouse or partner. Spouses and partners of the chronically ill or disabled can find online support here.

CAREGIVING FOR SPECIFIC PATIENT POPULATIONS

ALS Association—For Caregivers

<<http://www.alsa.org/als-care/caregivers/for-caregivers.html>>

The ALS Association, established in 1985, is a national nonprofit organization fighting amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig's Disease, through international research. It seeks to assist people with ALS via a nationwide network of chapters, coordinate multidisciplinary care through certified clinical care centers, and create government partnerships. A section for caregivers includes useful tips and helpful advice as well as contact information for their Care Connection program.

ALZ.org—Alzheimer's Association

<<http://www.alz.org/>>

The Alzheimer's Association is the leading, global, voluntary health organization for Alzheimer's care and support, and the largest private, nonprofit funder of Alzheimer's research.

American Heart Association—Caregiver

<http://www.heart.org/HEARTORG/Caregiver/Caregiver_UCM_001103_SubHomePage.jsp>

Caregiver rights, responsibilities, communication tips, and a well-developed resource section are just some of the useful topics covered in this portion of the larger American Heart Association web site. The information is designed to support the caregivers of individuals with cardiovascular diseases or stroke.

Disability.gov

<<https://www.disability.gov/>>

This federal government Web site offers comprehensive information on disability programs and services available nationwide. Caregiving resources are located under the Health subheading, and assistive technology resources are found under the subheading Technology.

National Multiple Sclerosis Society (NMSS)—Family Matters

<<http://www.nationalmssociety.org/Resources-Support/Family-Matters>>

Packed with resources, this page on the NMSS Web site offers free articles, brochures, and guidelines for family, friends, and caregivers on a variety of topics relevant to those with MS.

National Resource Center on LGBT Aging Resources—Caregiving

<<http://www.lgbtagingcenter.org/resources/resources.cfm?s=3>>

This Web page features publications from the Services and Advocacy for GLBT Elders (SAGE) and the National Resource Center on LGBT Aging. They are supported, in part, under a cooperative agreement from the U.S. Department of Health and Human Services, Administration on Aging. This section of the resource center addresses many important aspects of caregiving within the context of the LGBT population. Resources in multiple formats are provided, including PDF files, brochures, videos, audio files, newsletters, and Web sites (Figure 3).

Parkinson's Disease: Caregiver's Information

<<http://www.myparkinsons.org/>>

MyParkinsons.org supports researchers, physicians, occupational, physical and speech therapists, and psychological counselors. It also provides educational and medical information for Parkinson patients, their families and caregivers, neurologists, and general medical practitioners.

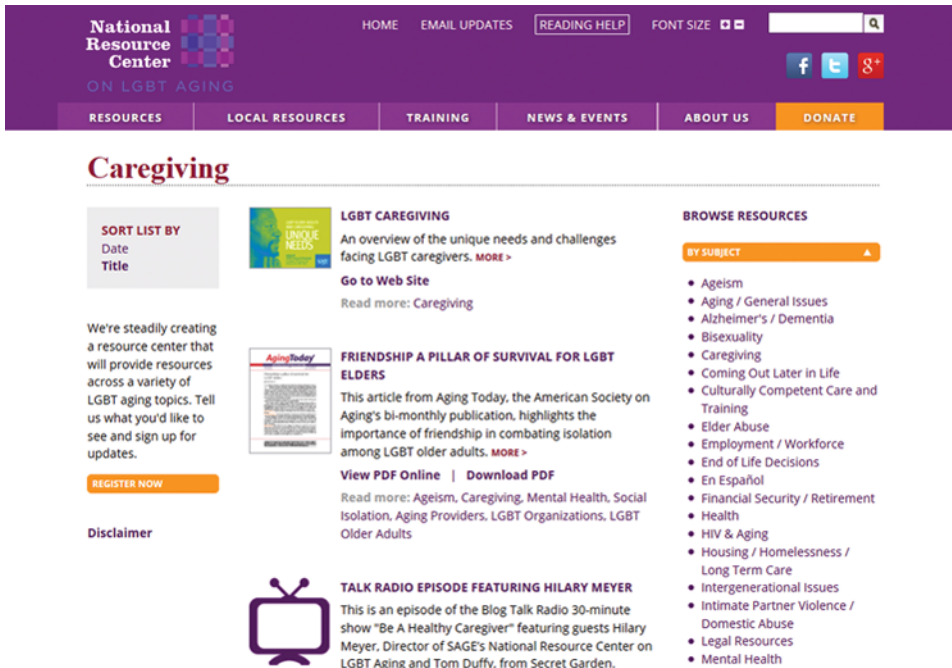


FIGURE 3 National Resource Center on LGBT Aging Resources: Caregiving Web page. © [National Resource Center on LGBT Aging Resources]. Reproduced by permission of Hilary Meyer, Director, National Resource Center on LGBT Aging. Permission to reuse must be obtained from the rightsholder.

ASSISTIVE TECHNOLOGY FOR CAREGIVING

Family Caregiver Alliance—Assistive Technology <<https://caregiver.org/assistive-technology>>

This fact sheet from the Family Caregiver Alliance explains the different types of assistive technology (AT) that may be helpful to caregivers and patients. In addition, it discusses how to find AT, how to pay for it, and how to decide what devices or home modifications may be needed. The fact sheet provides numerous links to credible AT Web sites and further information.

CAREGIVING VIDEOS

NIH SeniorHealth—Caring for Someone with Alzheimer's <<http://nihseniorhealth.gov/videolist.html#caringforsomeonewithalzheimers>>

NIH SeniorHealth is a consumer health information resource designed specifically for senior citizens. Topics are those of greater interest for older

adults, and the site provides visual support tools for those with low-vision and other vision problems. Of particular interest here is a collection of 17 brief (one to three minutes in length) video clips on the most typical questions asked by Alzheimer caregivers.

HBO Documentaries—The Alzheimer's Project
<<http://www.hbo.com/alzheimers/index.html>>

The Alzheimer's Project is a presentation of HBO Documentary Films and the National Institute on Aging at the National Institutes of Health, in association with the Alzheimer's Association[®], Fidelity[®] Charitable Gift Fund, and Geoffrey Beene Gives Back[®] Alzheimer's Initiative. It features a four-part documentary series, 15 short supplemental films, a detailed Web site, and links to a nationwide community-based information and outreach network. One of the documentaries, "Caregivers," highlights the joys and sorrows of people who share their loved one's dementia journey.

Pennsylvania Homecare Association (PHA)—My Learning Center
<<http://learningcenter.pahomecare.org/>>

The PHA is a state trade association representing more than 500 organizations providing homecare to individuals. My Learning Center offers 41 free, short videos on basic physical and emotional caregiving aspects, such as transferring, bathing, or dealing with aggression. Registration is free but required.

Terra Nova Films—videocaregiving.org
<<http://www.videocaregiving.org/>>

Videocaregiving.org is a visual education resource for family caregivers, from Terra Nova Films. The site provides 36 short videos depicting caregiving situations for families and patients afflicted with Alzheimer's. These brief documentaries are excellent for starting group discussions or for providing support for individual caregivers in their homes. The resource is especially useful for caregivers unable to participate in support groups in their home communities. The videos show real people facing challenges in actual caregiving scenarios.

YouTube
<<http://www.youtube.com/>>

Many associations, organizations and educational institutions have posted instructional videos useful to caregivers, patients, and their families. Use

the search box to locate caregiver-related topics such as “making an occupied bed,” “bathing a patient,” or “patient transfer.” Since content is not peer-reviewed, users must evaluate the quality and authority of the videos.

CONCLUSION

The types and needs of caregivers are many and varied. This growing population of helping individuals needs all of the support and information that it can get. Information professionals and library staff can assist caregivers by organizing resources and creating easily accessed gateways through online guides such as <<http://codlrc.org/HS/care>>, where targeted local, regional, and state resources can be highlighted.

REFERENCES

- Fox, Susannah, Maeve Duggan, and Kristen Purcell. 2013, June 20. Family caregivers are wired for health. *Pew Internet & American Life Project*. <http://www.pewinternet.org/Reports/2013/Family-Caregivers.aspx>
- National Alliance for Caregiving, and United Hospital Fund (NACUHF). 2005, September. Young caregivers in the U.S.: Report of findings. <http://www.aacy.org/publications/youngcaregivers.pdf>
- Witters, Dan. 2011, July 27. Caregiving costs U.S. economy \$52.2 billion in lost productivity. *Gallup, Inc.* <http://www.gallup.com/poll/148670/caregiving-costs-economy-billion-lost-productivity.aspx>