

## Caregiver Websites

Organization	Details
<p>AARP Caregiver Resource Center</p> <p><a href="http://www.aarp.org/home-family/caregiving/">www.aarp.org/home-family/caregiving/</a></p>	<p>Information, tools and tips for caregivers. Topics include: <a href="#">Planning &amp; Resources</a>, <a href="#">Benefits &amp; Insurance</a>, <a href="#">Legal &amp; Money Matters</a>, <a href="#">Care for Yourself</a>, <a href="#">Providing Care</a>, <a href="#">Senior Housing</a>, <a href="#">End of Life Care</a>, <a href="#">Grief &amp; Loss</a>, <a href="#">Prepare to Care Guide</a></p> <p><b>Phone: (877) 333-5885 Spanish: (888) 971-2013</b> <b>(Mon-Fri: 7 am-11 pm, Sat 9 am-5 pm)</b></p>
<p>Alzheimer's Association of Rochester and Finger Lakes Region</p> <p><a href="http://www.alz.org/rochesterny/">www.alz.org/rochesterny/</a></p>	<p>The Alzheimer's Association, Rochester &amp; Finger Lakes Region, has provided programs, services and advocacy since 1981 to individuals with Alzheimer's disease and other dementias, their families and health care providers. Serves a nine-county area that includes Chemung, Livingston, Monroe, Ontario, Schuyler, Seneca, Steuben, Wayne and Yates counties.</p> <p><b>Local Contact: (585) 760-5400</b>, Rochester &amp; Finger Lakes Region Chapter, 200 Meridian Centre Blvd. Suite 110, Rochester, NY 14618</p> <p><a href="#">Contact our staff.</a></p> <p><b>24/7 Helpline: (800) 272-3900</b></p>
<p>Brain injury Association of New York State (BIANYS)</p> <p><a href="http://bianys.org/about-bianys/mission-statement/">bianys.org/about-bianys/mission-statement/</a></p>	<p>Brain Injury Association of New York State (BIANYS) is a statewide non-profit membership organization that advocates on behalf of individuals with brain injuries and their families. Provides education, advocacy, and community support services for children and adults with brain injuries and families. Also offers a toll-free family help line, chapters and support groups throughout the state, prevention programs, professional development programs, and a video and publications library.</p> <p><b>Rochester Chapter Contact: Tory Chalmers (518) 459-7911</b></p> <p><b>Family Helpline: (800) 444-6443</b></p> <p><b>Email: <a href="mailto:rochesterchapter@bianys.org">rochesterchapter@bianys.org</a></b></p>
<p>Cancer Services Program of the Finger Lakes Region (CSP-FLR)</p> <p><a href="http://www.urmc.rochester.edu/community-health/community-programs/cancer-services-program.aspx">www.urmc.rochester.edu/community-health/community-programs/cancer-services-program.aspx</a></p>	<p>The CSP-FLR helps uninsured eligible men and women get cancer screenings. CSP-FLR pays for: Colon cancer screenings, Cervical cancer screenings, Mammograms, Clinical breast exams, Pelvic exams, Pap tests, Diagnostic tests. The CSP-FLR does not perform the screenings but pays for them at more than 200 clinics and providers across the</p>

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	<p>Finger Lakes Region. The Cancer Services Program serves individuals in Monroe, Seneca, Yates, Livingston, Wayne and Ontario Counties.</p> <p><b>Call (585) 224-3070. Outside of Monroe County, call (877) 803-8070</b></p>
<p>Caregiver Action Network</p> <p><a href="http://www.caregiveraction.org">www.caregiveraction.org</a></p>	<p>The Caregiver Action Network works to improve the quality of life for the more than 65 million Americans who care for loved ones with chronic conditions, disabilities, disease, or the frailties of old age. CAN serves a broad spectrum of family caregivers ranging from the parents of children with special needs to adult children caring for parents with Alzheimer’s disease. CAN (formerly the National Family Caregivers Association) is a non-profit organization providing education, peer support, and resources to family caregivers across the country free of charge.</p>
<p>Consumer Directed Personal Assistance Program (CDPAP)</p> <p><a href="https://www.health.ny.gov/health_care/medicaid/program/longterm/cdpap.htm">https://www.health.ny.gov/health_care/medicaid/program/longterm/cdpap.htm</a></p>	<p>This Medicaid program provides services to chronically ill or physically disabled individuals who have a medical need for help with activities of daily living (ADL’s) or skilled nursing services. Services can include any of the services provided by a personal care aide, home health aide, or nurse. Recipients have flexibility and freedom in choosing their caregivers. The person acting on the consumer’s behalf assumes full responsibility for hiring, training, supervising and –if necessary-terminating the employment of persons providing services.</p>
<p>Family Caregiver Alliance (National Center on Caregiving)</p> <p><a href="http://www.caregiver.org/">www.caregiver.org/</a></p>	<p>FCA supports and sustains caregivers with national, state and local programs and resources: <a href="#">National Center on Caregiving</a> –research, policy and practice, to advance the development of high-quality, cost-effective programs and policies for caregivers in every state; <a href="#">Family Care Navigator</a> helps caregivers locate support services by state.</p> <p>Services, education programs and publications are developed with caregivers’ needs in mind, to offer real support, essential information, and tools to manage the complex and demanding tasks of caregiving such as <b>Caregivers Guide to Understanding Dementia Behaviors</b> <a href="http://www.caregiver.org/print/17">www.caregiver.org/print/17</a></p>
<p>Family’s Guide to Caring for Parents</p> <p><a href="http://www.llmedico.com/a-family-guide-to-caring-for-aging-parents/">www.llmedico.com/a-family-guide-to-caring-for-aging-parents/</a></p>	<p>This simple guide takes you through the essential things caregivers need to take into account when considering in-home care in order to help your parents lead full, supported lives when they need it the most. Source: LL Medico, a home health care company, providing products and services to meet the needs of customers.</p>

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<p>Lifespan Texting Buddies Program (585) 244-8400 x 213 <a href="http://www.lifespan-roch.org/volunteer">www.lifespan-roch.org/volunteer</a></p>	<p>Trained volunteers are matched with caregivers to provide support and encouragement via text. Program is for all caregivers, not only dementia caregivers.</p> <p><b>Local Contact: Eve Moses, Lifespan, (585) 244-8400 x 213</b></p>
<p>Medicaid/New York State Department of Health  <a href="http://www.health.ny.gov/health_care/medicaid/">www.health.ny.gov/health_care/medicaid/</a></p>	<p>Medicaid is a government-sponsored insurance program for individuals of any age whose resources and income are insufficient to cover healthcare. Medicaid is a healthcare program that assists low-income families or individuals in paying for long-term medical and <a href="#">custodial care</a> costs. Medicaid is a joint program, funded primarily by the federal government and run at the state level, where coverage may vary. Medicaid is available only to individuals and families who meet specified criteria. Recipients must be legal residents or citizens of the United States.</p>
<p>National Caregivers Library  <a href="http://www.caregiverslibrary.org/caregivers-resources/grp-caregiving-basics-topic.aspx">www.caregiverslibrary.org/caregivers-resources/grp-caregiving-basics-topic.aspx</a></p>	<p>The National Caregivers Library was created by FamilyCare America, Inc. and is one of the largest single sources of information and tools for caregivers and seniors in the country. It makes its resources available to caregivers for free through alliances with professionals, businesses and other organizations who serve seniors and their caregivers with a variety of products and services</p>
<p>National Institute on Aging  <a href="http://www.nia.nih.gov/health/caregiving">www.nia.nih.gov/health/caregiving</a></p>	<p>The National Institute on Aging, NIA, one of the 27 Institutes and Centers of the National Institute of Health, leads the federal government in conducting and supporting research on aging and the health and well-being of older people. The Institute seeks to understand the nature of aging and the aging process, and diseases and conditions associated with growing older, in order to extend the healthy, active years of life.</p>
<p>New York State Caregiving and Respite Coalition  <a href="http://www.nyscrc.org/resources.htm">www.nyscrc.org/resources.htm</a></p>	<p>The New York State Caregiving and Respite Coalition (NYSCRC) is a partnership of dedicated organizations and individuals committed to supporting the millions of informal caregivers throughout the state. Through the Lifespan Respite Grant, NYSCRC is working to develop a comprehensive, sustainable program with the goal of training hundreds of volunteer respite providers throughout the state.</p> <p>The site provides links to websites for <a href="#">New York State Office for the Aging (NYSOFA)</a>, <a href="#">Monroe County: Caregivers Resource Guide</a>, <a href="#">Finger Lakes: The ElderPages Resource Guide</a>, <a href="#">AARP Caregiver Resource Center</a>, <a href="#">National Alliance for Caregiving</a>, <a href="#">ARCH National Respite Network</a>, <a href="#">Family Caregiver Alliance</a>, <a href="#">Kinship Navigator</a></p> <p><b>Local Contact: Eve Moses, Lifespan, (585) 244-8400 x 213</b></p>

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<p>New York Caregiver Portal</p> <p><a href="https://newyork-caregivers.com/login">https://newyork-caregivers.com/login</a></p>	<p>Care Network that develops and delivers healthcare training focused on senior care and aging-in-place. Provides educational content and learning environment to healthcare providers, insurers and employers in the United States (US) and Canada. Specialize in creating actionable training focused on critical skills and knowledge that families require to keep their aging parents and partners safe and healthy at home. Training is delivered on a proprietary learning management system that is personalized to each family's care situation and gamified with rewards and incentives to drive engagement. We believe that training family caregivers can improve outcomes and reduce costs of care for our aging population, while reducing the stress of caregiving.</p>
<p>Next Step in Care</p> <p><a href="http://www.nextstepincare.org/CaregiverHome/">www.nextstepincare.org/CaregiverHome/</a></p>	<p>Next Step in Care provides easy-to-use guides to help <a href="#">family caregivers</a> and <a href="#">health care providers</a> work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients.</p>
<p>Nursing Home Compare</p> <p><a href="http://www.medicare.gov/nursinghomecompare">www.medicare.gov/nursinghomecompare</a></p>	<p>Nursing Home Compare allows consumers to compare information about nursing homes. It contains quality of care information on every Medicare and Medicaid-certified nursing home in the country. <b>Note:</b> Nursing homes aren't included on Nursing Home Compare if they aren't certified to participate in Medicare or Medicaid. These Nursing Homes can be licensed by the state. For information about nursing homes not on this website, contact your <a href="#">State Survey Agency</a>. Information on Nursing Home Compare isn't an endorsement or advertisement for any nursing home and should be considered carefully.</p>
<p>Parkinson's Foundation</p> <p><a href="http://www.parkinson.org/living-with-parkinsons">www.parkinson.org/living-with-parkinsons</a></p>	<p>The Parkinson's Foundation Helpline provides specialists to help people with PD, caregivers and healthcare providers navigate every aspect of Parkinson's, offering emotional support, sharing current PD-related medical information and guiding callers to local resources.</p> <p>*The Helpline is available at (800) 4PD-INFO (473-4636) or email <a href="mailto:helpline@parkinson.org">helpline@parkinson.org</a>.</p> <p>For weekly online programs and events: <a href="http://www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-Health-at-Home">www.parkinson.org/Living-with-Parkinsons/Resources-and-Support/PD-Health-at-Home</a></p> <p>Home Safety Tips: <a href="http://www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Activities-of-Daily-Living/Home-Safety">www.parkinson.org/Living-with-Parkinsons/Managing-Parkinsons/Activities-of-Daily-Living/Home-Safety</a></p>
<p>Rochester Spinal Association</p> <p><a href="http://www.rochesterspinalassociation.org/">www.rochesterspinalassociation.org/</a></p>	<p>Programs and services provide support and information to individuals with spinal cord disability and their loved ones, care providers and professionals in the Greater Rochester region of N.Y.</p> <p>Spinal Cord Injury &amp; Disability Resource Manual <a href="http://www.rochesterspinalassociation.org/spinal-cord-resource-manual">www.rochesterspinalassociation.org/spinal-cord-resource-manual</a></p>

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Share the Care™ (STC)  <a href="https://sharethecare.org/caregivers-and-friends/">https://sharethecare.org/caregivers-and-friends/</a>	Since 1995, <i>Share the Care™ (STC)</i> has been the highly regarded guidebook and resource used by caregivers and their friends, neighbors, co-workers and acquaintances as a loving, pragmatic approach to caregiving that can succeed no matter what the challenge.  For a listing of additional resources, go to <a href="https://sharethecare.org/caregivers-and-friends/">https://sharethecare.org/caregivers-and-friends/</a>
So Far Away Long-Distance Caregiving: Twenty Questions and Answers <a href="https://order.nia.nih.gov/sites/default/files/2017-07/L-D-Caregiving_508.pdf">https://order.nia.nih.gov/sites/default/files/2017-07/L-D-Caregiving_508.pdf</a>	Developed by the National Institute on Aging (NIA), part of the National Institutes of Health, <i>Long-Distance Caregiving: Twenty Questions and Answers</i> focuses on some of the issues unique to long-distance caregiving. This booklet is a gateway to ideas and resources that raise and answers questions that can make long-distance caregiving more manageable and satisfying.
Springwell Caregiver’s Notebook - A Guide for Organizing and Record Keeping  <a href="https://springwell.com/resource/caregiver-notebook/">https://springwell.com/resource/caregiver-notebook/</a>	Springwell Caregiver’s Notebook <u>provides</u> a central place for caregivers to record and document the important aspects of your loved one’s care. This includes: Critical At A Glance Information, A Calendar for Schedule Tracking, Care Providers, Daily Routine and Care information, Medication Information, Health Information and Medical Events, Medical Professional Contact
The 40-70 Rule: A Guide to Conversation Starters for Boomers and Their Senior Loved Ones  <a href="http://www.caregiverstress.com/wp-content/uploads/2011/08/HomeInstead_40-70Booklet_Web.pdf">www.caregiverstress.com/wp-content/uploads/2011/08/HomeInstead_40-70Booklet_Web.pdf</a>	This guide is designed to help adult children and their aging parents deal with those sensitive life topics that often make conversations difficult. The “40-70 Rule” means that if you are 40, or your parents are 70, it’s time to start talking – at least about certain senior topics.  Also available is “The 70-40 Rule: A Guide to Conversation Starters for Seniors and their Boomer Children” <a href="http://www.caregiverstress.com/wp-content/uploads/2011/08/HomeInstead_40-70Booklet_Web.pdf">www.caregiverstress.com/wp-content/uploads/2011/08/HomeInstead_40-70Booklet_Web.pdf</a>

*The inclusion or exclusion of an entity does not constitute an endorsement or disapproval by Lifespan. We do not assume responsibility for the quality of services provided. Staff shall review the inclusion/exclusion policy on a regular basis to ensure the policy meets the needs of Lifespan. We reserve the right to exclude and/or remove any entity from the Lifespan system. Last Update: 5/4/2023*