



The Sojourner Project

...help for the journey

Caregiver School Resources

Part One - Becoming a family caregiver

This website and organizations have lots of general information to help you on your caregiving journey and have information and articles on a wide variety of topics

- www.Next.Avenue.org - News and information for people over 50 section dedicated to caregivers
- www.AARP.org/caregiving - A special section on family caregiving
- www.caregiver.org - Family caregiver Alliance
- www.familycaregiver.org - National Family Caregivers Association
- www.alz.org - The Alzheimer's Association has information that applies to all family caregivers

Part Two - Evaluating the situation

Normal aging:

- www.aoa.org - Administration on Aging
- www.nia.nih.gov - National Institute on Aging
- www.va.gov - Department of Veteran's Affairs
- www.n4a.org - National Area Agencies on Aging (to find your local agency)
- Alz.org - Early warning signs (vs. normal aging)

Driving

- www.seniordriving.aaa.com - Help and resources through the AAA
- www.nia.nih.gov - Older Drivers information and resources

Part Three - Make a Plan

- Download "Prepare to care: A Caregiving Planning Guide for Families" at www.aarp.org/caregiving
Or request a free hardcopy at (877) 333-5885 select option 1 Request item # D20152

Part Four - Navigating the medical world

- www.Medicare.gov or (800) MEDICARE
- www.Medicaid.gov
- www.Healthcare.gov - Insurance information through the Affordable Care act
- Healthcare Navigator through Medicare Find help and information n finding the right health insurance plans either on line at Medicare.gov or in person at your local Area on Aging Office find you local office at www.n4a.org
- www.mayoclinic.org - For the latest information on disease, symptoms and treatment options
- www.cancer.org American Cancer Society provides information, education and local resources

Part Five - Legal & Financial affairs

- www.ssa.gov - Social Security Administration
- medicare.gov - The official Medicare website
- www.Healthcare.gov - The official government website for information on insurance plans offered through the (ACA) Affordable Care Act
- www.va.gov - Department of Veteran's Affairs

This information is for educational purposes only and does NOT provide any legal, medical or financial advice.
The goal is to provide general information so that you can seek out professional assistance from the appropriate subject matter expert

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Resources (continued)

Part Five - Legal & Financial affairs (continued)

- www.NAELA.org - National Association of Elder Law Attorneys - To locate an attorney near you who specializing in Trust and Estate Planning
- www.NHPCO.org - Download the Legal Guide for the Seriously ill 7 Key Steps to get your affairs in order
- www.CaringInfo.org - Free State specific Advance Directive Forms and detailed instructions
- www.FiveWishes.org - The Five Wishes is more than an advanced directive covering end of life choices
- www.CancerLegalResources.org - download the Cancer Legal Resources Center's "Patient Legal Handbook"
- www.cms.gov - Search for information and forms on Medicaid waivers
- www.NAIC.org - National Association of Insurance Commissions - Search to find your state insurance commission to learn about your rights and options regarding Long Term Care Insurance
- www.LongTermCare.gov - US Department of Health provides information on LTC costs and insurance
- www.Consumerfinance.gov - Help and information on managing someone else's money
- www.caregiver.org/personal-care-agreements - The Family Caregiver Alliance has information on how to compensate a family member for providing care through a contract or "Caregiver Agreement"

Part Six - Day to day caregiving

At home

- www.benefits.gov - Use this tool to find all of the programs, agencies that you qualify for in your area.
- www.thiscaringhome.org - This Caring Home has information and suggestions on making your home safer
- www.mealsonwheelsamerica.org - To find your local MOW program for home delivered meals
- www.n4a.org - National Agency for Aging (search for local office) to connect to community based services
- www.unitedway.org or call 211 for help finding local services and resources available to help
- www.va.gov - Department of Veteran's Affairs
- www.Medicare.com - Use their Find Home Health Services to learn about these agencies and their services
- www.medicare.gov - search for DME to learn about the Durable Medical Equipment available
- www.lifealert.com Only one of the many companies /options for personal alarms systems
- www.ConsumerFinance.gov - The Consumer Finance Protection Bureau has information on how to avoid fraud and scams

Professional Care Facilities

- www.Medicare.com - Use their Finding a Nursing Home link and download their Guide to choosing a Nursing Home and The Free Nursing Home Checklist to use when visiting residential facilities.
- www.aplaceformom.com - A private organization that offers free assistance to families searching for residential care facilities. Great informative website even if you don't use their locator services.
- LTC ombudsman

Long Distance Caregiving

- www.nia.nih.gov Download/order the booklet "Long Distance Caregiving, 20 questions and answers"

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Part Seven - When things get complicated - Understanding Dementia & Alzheimer's disease

- www.alz.org :
 - Learn the early warning signs and the stages of the disease
 - Video "Inside the Brain, a Tour of how the Mind Works" to learn how disease affects functioning
 - Download free booklets with information and suggestions on how to manage difficult behaviors, such as repetition, suspicion and wandering.
 - Take advantage of their extensive on-line and community based education and training programs
- www.caregiver.org "Ten tips for communicating with a person with dementia"
- www.nia.nih.gov - "Home safety checklist for Alzheimer's Disease"
- www.APlaceforMom.com - For help finding specialized memory and dementia care facilities
- Book: The 36 Hour Day; A Family Guide to Caring for People who have Alzheimer Disease, Other Dementia and Memory Loss by Nancy L Mace & Peter V Rabins
- Movie: "Still Alice"

Part Eight - Caring for the caregiver

- www.alz.org "Ten signs of caregiver stress"
- Rest Stops - Caregiver School - One minute Meditations for the Family Caregiver
 - <http://patthorne.com/river-stop/>
 - <http://patthorne.com/caregiver-school/rain-stop/>
- Book: Wherever you go there you are; Mindfulness and Meditation in Everyday Life by Jon Kabat Zinn
- Download the meditation apps: Calm or Headspace
- Watch Marty Boroson's YouTube video "How to Meditate in a Moment"
 - Or go to his website www.onemomentcompany.com

Part Nine - When the journey ends

Death & Dying

- www.nhpc.org - The National Hospice & Palliative Care Organizations website will answer your questions concerning hospice and will help you locate an agency that services your area
- www.WebMD.com "What to expect when your loved one is dying"
- www.CrossroadsHospice.com "A guide to understanding end of life signs and symptoms"
- www.Caring.com "How to say good-bye when someone you love is dying"
- www.Next.org "How to plan a funeral"
- www.FTC.gov The Federal Trade Commission The Funeral Rule information on funeral regulations, cost and your rights
- Recommended reading
 - On Death and Dying by Elizabeth Kubler Ross, MD
 - Dying Well by Ira Byok, MD
 - The Needs of the Dying by David Kessler
 - Final Gifts by Maggie Callahan

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Part Nine - When the journey ends (continued)

Grief & Loss

- Grief.com - David Kessler teaches About Grief in 12 video lessons
- Griefshare.org - A grief recovery support group
- Books:
 - On Grief and Grieving Elizabeth Kubler-Ross & David Kessler
 - A Grief Observed by CS Lewis
 - It's Ok You're Not OK: Meeting Grief & Loss in a Culture that Doesn't Understand -Megan Devine
 - The Year of Magical Thinking by Joan Didion
 - Option B: Facing Adversity, Building Resilience, and Finding Joy - Sheryl Sandburg & Adam Grant
 - Mourning and Dancing: A memoir of Grief and Recovery by Sally Miller