



## 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](http://www.Next.Avenue.org) - News and information for people over 50 section dedicated to caregivers
- [www.AARP.org/caregiving](http://www.AARP.org/caregiving) - A special section on family caregiving
- [www.caregiver.org](http://www.caregiver.org) - Family caregiver Alliance
- [www.familycaregiver.org](http://www.familycaregiver.org) - National Family Caregivers Association
- [www.alz.org](http://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](http://www.aoa.org) - Administration on Aging
- [www.nia.nih.gov](http://www.nia.nih.gov) - National Institute on Aging
- [www.va.gov](http://www.va.gov) - Department of Veteran's Affairs
- [www.n4a.org](http://www.n4a.org) - National Area Agencies on Aging (to find your local agency)
- [Alz.org](http://Alz.org) - Early warning signs (vs. normal aging)

Driving

- [www.seniordriving.aaa.com](http://www.seniordriving.aaa.com) - Help and resources through the AAA
- [www.nia.nih.gov](http://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](http://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](http://www.Medicare.gov) or (800) MEDICARE
- [www.Medicaid.gov](http://www.Medicaid.gov)
- [www.Healthcare.gov](http://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](http://Medicare.gov) or in person at your local Area on Aging Office find you local office at [www.n4a.org](http://www.n4a.org)
- [www.mayoclinic.org](http://www.mayoclinic.org) - For the latest information on disease, symptoms and treatment options
- [www.cancer.org](http://www.cancer.org) American Cancer Society provides information, education and local resources

#### Part Five - Legal & Financial affairs

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

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### Caregiver School Resources *(continued)*

#### Part Five - Legal & Financial affairs (continued)

- [www.NAELA.org](http://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](http://www.NHPCO.org) - Download the Legal Guide for the Seriously ill 7 Key Steps to get your affairs in order
- [www.CaringInfo.org](http://www.CaringInfo.org) - Free State specific Advance Directive Forms and detailed instructions
- [www.FiveWishes.org](http://www.FiveWishes.org) - The Five Wishes is more than an advanced directive covering end of life choices
- [www.CancerLegalResources.org](http://www.CancerLegalResources.org) - download the Cancer Legal Resources Center's "Patient Legal Handbook"
- [www.cms.gov](http://www.cms.gov) - Search for information and forms on Medicaid waivers
- [www.NAIC.org](http://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](http://www.LongTermCare.gov) - US Department of Health provides information on LTC costs and insurance
- [www.Consumerfinance.gov](http://www.Consumerfinance.gov) - Help and information on managing someone else's money
- [www.caregiver.org/personal-care-agreements](http://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](http://www.benefits.gov) - Use this tool to find all of the programs, agencies that you qualify for in your area.
- [www.thiscaringhome.org](http://www.thiscaringhome.org) - This Caring Home has information and suggestions on making your home safer
- [www.mealsonwheelsamerica.org](http://www.mealsonwheelsamerica.org) - To find your local MOW program for home delivered meals
- [www.n4a.org](http://www.n4a.org) - National Agency for Aging (search for local office) to connect to community based services
- [www.unitedway.org](http://www.unitedway.org) or call 211 for help finding local services and resources available to help
- [www.va.gov](http://www.va.gov) - Department of Veteran's Affairs
- [www.Medicare.com](http://www.Medicare.com) - Use their Find Home Health Services to learn about these agencies and their services
- [www.medicare.gov](http://www.medicare.gov) - search for DME to learn about the Durable Medical Equipment available
- [www.lifealert.com](http://www.lifealert.com) Only one of the many companies /options for personal alarms systems
- [www.ConsumerFinance.gov](http://www.ConsumerFinance.gov) - The Consumer Finance Protection Bureau has information on how to avoid fraud and scams

##### Professional Care Facilities

- [www.Medicare.com](http://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](http://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](http://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](http://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](http://www.caregiver.org) "Ten tips for communicating with a person with dementia"
- [www.nia.nih.gov](http://www.nia.nih.gov) - "Home safety checklist for Alzheimer's Disease"
- [www.APlaceforMom.com](http://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](http://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](http://www.onemomentcompany.com)

#### Part Nine - When the journey ends

##### Death & Dying

- [www.nhpco.com](http://www.nhpco.com) - 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](http://www.WebMD.com) "What to expect when your loved one is dying"
- [www.CrossroadsHospice.com](http://www.CrossroadsHospice.com) "A guide to understanding end of life signs and symptoms"
- [www.Caring.com](http://www.Caring.com) "How to say good-bye when someone you love is dying"
- [www.Next.org](http://www.Next.org) "How to plan a funeral"
- [www.FTC.gov](http://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](http://Grief.com) - David Kessler teaches About Grief in 12 video lessons
- [Griefshare.org](http://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