



## The New Intergenerational Challenge Caring for Aging Parents A Resource List for Caregivers and Recipients





## Finding the Right Resource

Modern medicine has enabled far longer lifespans than ever before. While this is an overall positive development, it also means that many of us will spend years as a caregiver of parents and aging loved ones or as a recipient of that care. Regardless of the strength of a family's relationships or the extent of their resources, the associated legal, emotional, medical and financial issues involved can be overwhelming.

One of the hardest aspects is the sense of isolation and loneliness that often accompanies aging and caregiving. The good news is that none of us are alone in this process. The number of organizations, books, websites and professionals assisting across many different aspects of aging continues to grow. We created this guide to help caregivers and recipients find a starting point for navigating this increasingly common journey.

Whether your family is facing this situation in the short or long term, and whether you are in the role of caregiver or receiver, we hope this guide is useful in identifying the resources and expertise to assist you and your family.

A special thanks to Mardy Chizek, Larry Frolik and Jim Grubman for their contributions to the development and editing of this resource list.

## **Books for Caregivers**



Alzheimer's

Early

Stages

#### Can't We Talk About Something More Pleasant?: A Memoir Roz Chatz

Beloved New Yorker cartoonist and author, Roz Chatz, shares the very personal story of being a caretaker for her elderly parents and the impact on her life and theirs. Recognizing and using humor as one way of coping with the grief and guilt that comes with moving parents from their home to care facilities and the shift in relationship from child to caretaker, this is a very honest look at the very difficult experience that adult children have in caring for their parents.

## Alzheimer's Early Stages: First Steps for Family, Friends, and Caregivers Daniel Kuhn, MSW and David A. Bennett, MD.

Strong focus on the early stages of Alzheimer's disease, with information on how families can better understand and cope with its effects as their loved one begins to experience cognitive and behavioral changes. It includes suggestions on how to handle caregiver stress.

# <text>

#### The 36-Hour Day: A Family Guide to Caring for People With Alzheimer's Disease, Other Dementias, and Memory Loss in Later Life Nancy L. Mace and Peter V. Rabins

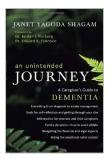
Long considered to be one of the most essential guides for families dealing with dementia and Alzheimer's, this book features practical advice covering all aspects of care – from the emotional to the legal and financial.

## Understanding Difficult Behaviors: Some Practical Suggestions for Coping with Alzheimer's Disease and Related Illnesses



#### A. Robinson, B. Spencer, and L.White

This book helps families and caregivers understand why challenging behaviors occur in people with dementia and Alzheimer's disease, how to communicate, and how to cope. These suggestions have been compiled from a various sources including conversations with families, Alzheimer's Association newsletters, books and journal articles.



#### An Unintended Journey: A Caregiver's Guide to Dementia

#### Janet Yagoda Shagam

This book addresses the challenges faced by adult children and other family members who are trying to make sense of what is happening to themselves and the loved ones in their care. It also covers topics not usually included in other books on dementia: family dynamics, caregiver burnout, finances and paying for care, and coping with the eventuality of death and estate management.

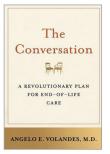
## **Books for Seniors**



#### From Age-ing to Sage-ing: A Revolutionary Approach to Growing Older

Zalman Schachter-Shalomi and Ronald S. Miller

Given the value Western culture places on youth, many people fear the aging process and see little to look forward to in their later years. Facing these same fears in his own life, Rabbi Schacter-Shalomi spent years study different cultures and spiritual teachings about aging. His writing turns our typically negative perceptions of aging and dying on its head and introduces a new philosophy of embracing this phase in life as a wise elder. In a process he calls "Spiritual Eldering", the Rabbi explains the role of our elders in social activism, creating awareness, and mentoring the next generation.



#### The Conversation: A Revolutionary Plan for End-of-Life Care Angelo Volandes

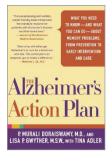
Through the stories of seven patients and seven very different end-of-life experiences, this book demonstrates that what people with a serious illness, who are approaching the end of their lives, need most is not new technologies but one simple thing: The Conversation. It offers ways for patients and their families to talk about this difficult issue to ensure that patients will be at the center and in charge of their medical care.

#### **Capturing Family Legacy**

One of the greatest gifts that any of us can pass on to our children and grandchildren is the stories of our lives and the values we want to share with them. The following professionals specialize in capturing family and individual history.

- Docyoumentary, www.docyoumentary.com
- Legacy Multimedia, www.legacymultimedia.com
- Personal Legacy Advisors, LLC, www.personallegacyadvisors.com
- Video Family Biographies, www.videofamilybiographies.com
- Whole Story Productions, www.wholestoryproductions.com

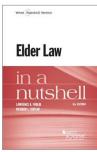
## Legal and Medical Issues

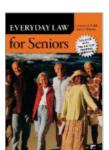


## The Alzheimer's Action Plan: The Experts' Guide to the Best Diagnosis and Treatment for Memory Problems

#### P. Murali Doraiswamy and Lisa Gwyther

In addition to providing a guide to diagnosis and treatment methods, this book outlines coping strategies for life after diagnosis, what to expect from different stages of the disease and how to participate in clinical trials.





Atul Gawande

Being Mortal

Medicine and What Matters in the End

#### Elder Law in a Nutshell, 6<sup>th</sup> edition Lawrence A. Frolik and Richard Kaplan

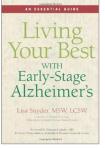
This edition covers topics including elder abuse and neglect, criminal background checks of workers who work with older patients, major Medicare changes, end-of-life planning, tax increases on both earned and investment income, and more.

#### Everyday Law for Seniors: Updated with the Latest Federal Benefits Lawrence A. Frolik and Linda S. Whitton

This resource provides easy-to-understand information to make the best possible decisions about retirement options, health care, where to live, and planning for long-term care. It explains a wide range of legal rights and benefits for every senior and for everyone who wants to get the most from their senior years.

## Being Mortal: Medicine and What Matters in the End Atul Gawande

Surgeon, long-time staff writer for the New Yorker and Harvard Professor Atul Gawande tackles one of the hardest issues facing modern medicine – how to not only extend life but enable and even assist the end-of-life process. This book offers examples of more socially fulfilling models for assisting the elderly and infirm where the emphasis is on quality as opposed to length of life. Gawande also outlines varieties of hospice care so that a person's last weeks or months may be rich and dignified.



#### Living Your Best With Early Stage Alzheimer's: An Essential Guide Lisa Snyder

When a person is diagnosed, they may have many years ahead with only mild symptoms. Therefore, a growing number of people with early-stage Alzheimer's seek information about how to take charge of their lives, manage symptoms, and cope effectively with the disease.

## Resources

### Websites

#### www.aarp.org

The AARP website is a valuable resource for both seniors and caregivers. The site's caregiving section includes online communities, articles, videos and an "ask the expert" section. There is also a Locate Resources section where users can locate caregivers in their area.

#### www.acpdecisions.org

This website was created by Angelo Volandes, MD, MPH, physician and researcher at Harvard Medical School and Massachusetts General Hospital and author of The Conversation: A Revolutionary Plan for End of Life Care (see books in this guide.) The website includes short, easy-to-understand videos for patients and their families along with tools that families and patients can use to document their own care preferences.

#### www.alz.org

The Alzheimer's Association website provides useful information to those afflicted with the disease as well as those caring for them. It covers the wide range of medical, legal, financial and emotional issues that are part of managing life and caregiving with Alzheimer's. This site also has good information on dementia.

#### www.caremanager.org

The website of the National Association of Geriatric Care Managers (NAGCM). A very informative site that provides information for families and advisors, with a searchable database for finding a care manager in your area.

#### www.aftergiving.com and www.caregiving.com

Both of these sites are operated by Denise M. Brown. Denise is a professional caregiving coach, working with family caregivers and professionals to find the meaning in their journeys. Caregiving.com features the blogs of family caregivers, weekly words of comforts, weekly self-care plans, weekly chats, a Community Caregiving Journal, free webinars, and online support groups. AfterGiving.com is a community of former family caregivers providing support and sharing their experiences of transitioning into life after caregiving.

#### www.seniorhousingnet.com

A division of realtor.com, this site provides a search function to view available housing options by location across a wide range of categories – independent living, senior communities, assisted living and special care facilities. This site also includes an extensive "advice" section that covers many topics that should be considered in senior housing decisions and later life planning.

#### www.polst.org/about-the-national-polst-paradigm

POLST (Physician Ordered Life Sustaining Treatment) has replaced the Do Not Resuscitate (DNR) form for many states. This site helps the consumer understand that the decision-making concerning end of life is a personal decision and that the consumer needs to be informed about their choices. Some state POLST forms can be found on this site or there is a link to take users to the state site for the correct form.

#### www.ipa-online.org/wordpress/publications/ guides-to-bpsd

The behavioral and psychiatric symptoms (BPSD) of dementia are often even more difficult to manage and accept than the memory loss that accompanies the disease. BPSD symptoms indicate an ailing brain and may require both individualized behavioral interventions as well as medications to manage them and keep the cognitively impaired person safe and dignified.

#### Blogs

#### Alzheimer's Reading Room

#### www.alzheimersreadingroom.com

The Alzheimer's Reading Room is consistently voted the number one blog by notable outlets like the New York Times. Editor Bob DeMarco cared for his mother as she bravely fought Alzheimer's in her final years. He continues to add to the more than 4,000 video and editorial items stored on the site. Topics include information that will help, educate, and support caregivers: from those just beginning their care journey to those who are more familiar with the course of the disease.

#### **Caregiving With Purpose**

#### www.caregivingwithpurpose.com

This is a bright, uplifting blog by Dr. Ina Gilmore. She presents and analyzes the latest Alzheimer's news from the perspective of decades of professional experience. Features include long-distance caregiving, crafts for caregivers and patients, and balancing costs with responsibilities.

#### Helping Parents Age Well

#### www.helpparentsagewell.blogspot.com

This blog isn't just about helping our parents. The information and insight on this blog are useful to anyone who anticipates living beyond middle age. Key thoughts include "Will these actions I'm about to undertake empower or diminish?" and "Does the quick fix harm later goals?" The focus is on values and long-term solutions, making for a good life-coaching guide and regular reading.

#### **Professionals**

#### Attorneys

#### www.actec.org

The American College of Trust and Estate Counsel (ACTEC), an invitation-only association, comprises many of the nation's leading estate planners who are knowledgeable about the needs of clients concerned with their aging and that of their parents. Its website provides a list of members by state.

#### www.naela.org

The National Academy of Elder Law Attorneys (NAELA is a professional association of attorneys who specialize in providing legal assistance to individuals as they age and for individuals with special needs. Many of its members are very experienced in handling issues of guardianship and finding providers and paying for longterm care. Its website provides a list of its 4,200 members.

#### Geropsychiatrists

#### www.aagponline.org

The American Association of Geriatric Psychiatrists is the professional organization for psychiatrists who have special training and expertise in the treatment of seniors with behavioral health conditions and those with BPSD (Behavioral and Psychiatric Symptoms of Dementia). These physicians are an important team member in the management of the behavioral signs and symptoms of dementia regardless of the cause.

#### Neuropsychologists

Neuropsychologists are very often consulted clinically by physicians to help diagnose dementia or forensically to help assess capacity in legal or financial situations. Some neuropsychologists also provide ongoing consultation (beyond just assessment) to help family members navigate the caregiving process over time. Advocate to get a neuropsychologist involved if there are significant questions about diagnoses or abilities of



your loved one. You can do online searches for credentialed neuropsychologists in your local area at the websites of several organizations:

National Academy of Neuropsychology www.nanonline.org American Academy of Clinical Neuropsychology www.theaacn.org

International Neuropsychological Society www.the-ins.org

#### **PinnacleCare**

#### www.pinnaclecare.com/individuals/eldercare

PinnacleCare is a subscription based medical concierge service that provides individuals and families with access to top doctors and medical facilities as well as expert guidance through the complex health care system. Their eldercare services includes the ongoing assistance of a private health advisor for scheduling and attending doctor's appointments as well as helping the family weigh options for housing and medical treatment. Note: Altair clients receive a 25% discount on PinnacleCare's set-up fee.

#### For families who would like to work one-on-one with an expert, the following is a list of independent specialists.

#### Mardy Chizek, RN

Mardy Chizek is a registered nurse and nurse practitioner who has four decades of experience as a healthcare provider and manager, consultant, senior advocate and navigator. Her collaborative approach integrates healthcare, legal, psychosocial, financial and behavioral health for the senior and their family. She is a United States Air Force veteran. **Phone**: 630.515.9223 **Email**: charism@charism.net **Website**: www.charism.net

#### Lawrence A. Frolik

Professor Frolik is a national expert on the legal issues facing older Americans. One of the founders of the field of elder law, he is the author, co-author or editor of over a dozen books. He is an honors graduate of Harvard Law School. Phone: 412.648.1363 Email: frolik@pitt.edu

#### Jim Grubman PhD

Dr. Grubman provides consultation to ultra-high-networth families about complex issues facing the family, including the impact of medical crises and factors affecting generational succession and transition. His background in neuropsychology and behavioral medicine allows him to assess situations and make recommendations for families struggling with difficult legal, financial, and healthcare decisions. **Phone:** 413.775.0557 **Email:** jim@jamesgrubman.com

Website: www.jamesgrubman.com

#### Circle of Life Partners

Founded by Janet Benvenuti, a former scientist and educator, pharmaceutical executive and management consultant, Circle of Life Partners helps families identify the guidance and direct assistance they need to manage the care of aging parents. Janet and her team provide family consultations to review a client's full legal, financial, health care and housing needs and develop a customized plan for taking care of their loved one.

Phone: 978-287-5600 Email: janet@colpartners.com Website: www.colpartners.com



## Altair Advisers

#### **About Altair**

Altair Advisers is an independent wealth advisory firm providing investment management, financial planning and client education services. We advise a select group of individuals, families, foundations and endowments. As a fiduciary, we serve as an advocate for our clients, providing objective advice and comprehensive guidance across all aspects of our clients' financial lives.

Our goal is to simplify the complexities of wealth so that you can pursue and enjoy the opportunities it enables.

#### Advice for Your Full Financial Picture

Like a symphony, your wealth consists of many different components that must complement and balance each other. Our three-part service offering supports your full wealth management needs. Whether designing a portfolio to achieve specific investment goals, reviewing a long-held insurance policy or determining the best way to talk about family trusts with young adults, we work in close collaboration with you and your other professional advisors to ensure an integrated approach to your wealth planning.

#### Wealth Guidance for Life Decisions

Wealth decisions are life decisions and they are influenced by both predictable and unexpected events – marriage, birth of a child, death in the family, sale of a business, change in health, relocation or retirement, divorce. We understand that emotions naturally play a role in how you evaluate financial options and see it as our job to provide evenhanded advice within your assessment process. As your life and financial needs evolve over time, our disciplined structure ensures your wealth planning remains relevant and current.

#### For More Information Visit www.altairadvisers.com or Contact:

Anna Nichols Director of Communications 312.429.3011 anichols@altairadvisers.com

This document has been prepared by Altair Advisers LLC for its clients and associates. The views and recommendations contained within this document are those of the authors at the time of writing. Should you have any questions regarding the material contained herein, or need further assistance regarding these or other issues, please direct all inquiries to 312.429.3000 or info@altairadvisers.com.

The material shown is for informational purposes only. Forward-looking statements are subject to numerous assumptions, risks, and uncertainties, and actual results may differ materially from those anticipated in forward-looking statements. As a practical matter, no entity is able to accurately and consistently predict future market activities, and all investments are subject to the risk of loss. While efforts are made to ensure information contained herein is accurate, Altair Advisers LLC cannot guarantee the accuracy of all such information presented. Material contained in this publication should not be construed as accounting, legal, or tax advice.

©2017 Altair Advisers LLC. All Rights Reserved.



#### Altair Advisers LLC

303 West Madison Street, Suite 600 Chicago, Illinois 60606 312.429.3000

altairadvisers.com

Connect with us:

