

APPENDIX

RESOURCES

AARP Caregiver Identification Study, AARP, February 2001.

Family Caregiving in the U.S.: Findings from a National Survey, National Alliance for Caregiving and AARP, June 1997.

A National Report on the Status of Caregiving in America, National Family Caregivers Association, November 1999.

Family Caregiver Fact Sheet, Administration on Aging, U.S. Department of Health and Human Services, May 1999.

America's Families Care: A Report on the Needs of America's Family Caregivers, Administration on Aging, U.S. Department of Health and Human Services, January 2001.

Work and Elder Care: Facts for Caregivers and Their Employers, U.S. Department of Labor, May 1998

Family Caregiving: An Agenda for Action, National Health Council, August 2000.

Chronic Illness and Caregiving: Survey of the General Public, Adults with Chronic Conditions and Caregivers, The Robert Wood Johnson Foundation and Johns Hopkins University, Partnership for Solutions, February 2000.

National Survey on Health Care and Other Elder Care Issues, Henry J. Kaiser Family Foundation, September 2000.

Always on Call: When Illness Turns Families Into Caregivers, edited by Carol Levine, United Hospital Fund, New York 2000.

SEARCHING FOR FAMILY CAREGIVING MATERIALS

National Family Caregivers Association (NFCA) and National Alliance for Caregiving (NAC) are requesting organizations to share information as we begin the research and development phase of our long-planned "Family Caregiver Self-Awareness Project." When our research is completed, we will develop the program into a nationwide, ongoing, public education campaign designed to help family caregivers acknowledge their caregiving role — and the needs that arise from that role. Family caregivers underpin our nation's health care system and dramatically improve the quality of life for those whom they care for, yet their situations create tremendous needs for themselves. Our program will empower family caregivers to become their own advocates, so that they can continue effectively and productively in their caregiving roles, their work, and their personal lives. **The long-term objective of our project is to improve the overall quality of life for caregivers, which in turn improves the quality of caregiving for recipients of care.**

We are requesting that colleagues provide any examples of work that has been done in this area, to ensure that we do not waste precious resources duplicating effort and that we learn from the experience of others.

If your organization, or any other organization you know of, has conducted any research or produced any material —for family caregivers — that directly encourages them to be more aware of their situation, speak up for their own needs, and take charge of their lives, we would like to know about it.

If you have conducted research, seminars, produced brochures, videos, manuals, advertisements, or done other activities, please send us a copy. Again, we are *not* looking for materials on caregiving in general, but for **materials that are specifically designed to help caregivers become more aware of, engaged in, and empowered in their own evolving roles as caregivers.**

For questions please call 301-972-6430, or email: melanehoff@aol.com, or send materials, articles and reports to: Melane Kinney Hoffmann, Project Director, NFCA, 10400 Connecticut Avenue, Suite 500, Kensington, MD 20895-3944.

**SUMMARY OF COMMUNICATIONS AUDIT
FOR
FAMILY CAREGIVERS SELF-AWARENESS PROJECT**

Note: In reviewing organizations for which the main emphasis is NOT caregiving and few caregiving pieces exist, all available items are reviewed individually below. For organizations whose main focus is caregiving, the materials were reviewed in the aggregate. Upon follow-up phone calls, many organizations referred us to their web sites to obtain their caregiving materials.

Organization	Item	Topics Covered (see codes, below table)	Target Audience	Comments
1. AARP and www.aarp.org	Video (24 minutes) and brochure: Survival Tips for New Caregivers	1-14, 16	Acknowledged caregivers	Emotionally supportive tone
2. AARP	Web site brochure, "Caregiving: Managing Stress When Giving Care"	6, 8, 13, 14, 16	Acknowledged caregivers	Emotionally supportive tone
3. AARP	Article in monthly newsletter, <i>Bulletin</i> , "Outwitting Dementia: A Daughter's Story"	3 – 8, 13, 14, 16	Acknowledged and unacknowledged caregivers	Emotionally supportive tone
4. Alzheimer's Association and www.alzheimers.org	Web site brochures, "A Caregiver's Guide," "Are You a Healthy Caregiver?" and "Caregiver Stress"	6-8, 9 – 12, 13, 14, 16	Acknowledged caregivers	Offers practical tips for staying healthy and reducing stress.
5. Alzheimer's Association	A Caregiver and Patient Resource List	NA	Acknowledged caregivers	Most resources focus on how to care for Alzheimer's patients, minor focus on the caregiver
6. American Academy of Family Physicians and www.aafp.org	Article in <i>American Family Physician</i> , "A Practical Guide for Caregivers"	NA	Family Physicians	Provides the Zarit Burden Interview and "Suggested Questions for Assessing Caregiver Burden During an Office Visit"
7. American Academy of Family Physicians	Web site brochure, "When You Are the Caregiver"	1, 2, 7, 8, 16	Acknowledged and unacknowledged caregivers	Defines caregiving, encourages use of respite, offers resources. Supportive.
8. American College of Physicians-American Society of Internal Medicine online and www.acponline.org	Home Care for Advanced Cancer: Getting "Respite" Care or Extra Help at Home	11, 13, 14, 16	Primarily Acknowledged caregivers	Main focus is on defining respite, encouraging caregivers to seek respite care and how to go about it. In providing rationale for getting respite care, addresses some "self identification" issues, e.g., "when to get help"
9. American Medical Association and www.ama-assn.org	Self-Assessment Questionnaire: How are You?	N/A	Physicians to provide to caregivers	Objective is to help physicians acknowledge the role of caregivers and screen them for health concerns

Organization	Item	Topics Covered (see codes, below table)	Target Audience	Comments
10. American Nurses Association and www.ana.org	Position Statement: "Informal Caregiving"	1,2,3,4	Policy makers, executives and program managers in the caregiving arena	Provides ANA's position on the importance of family caregiving
11. American Occupational Therapy Association and www.AOTA.org	Web site brochure, "Caring for the Caregiver"	3, 8, 11, 16	Occupational Therapists and their patients' caregivers	Practical tips for reducing stress
12. Children of Aging Parents and www.caps4caregivers.org	Web site brochure, "Caregiver Guide"	9	Adult child of aging parents	Emphasis is on financial, legal and logistical planning for an aging parent
13. Caregiver Assistance Network, Catholic Social Services of Cincinnati, OH	Identity brochure to offer resources to caregivers	1,6,13,14, 16	Acknowledged caregivers	Defines "caregiver" along with other terms, especially promotes respite and support groups
14. Easter Seals and www.easter-seals.org	Web site brochure, "Are You a Caregiver?"	1-4, 6-8, 13, 14, 16	Acknowledged and unacknowledged caregivers	Emotionally supportive, addresses the importance of acknowledging caregiver role
15. Family Caregiver Alliance and www.caregiver.org	More than 40 publications and a Resource List	1-8, 9-12, 13, 14, 16, 17	All publications are for acknowledged caregivers	Fact sheets and publications focus on various topics.
16. Family Voices and www.familyvoices.org	Two survey reports on experiences of parents of children with special needs; Additional Report on the Family Partners Project	1-7	Parent caregivers and professionals in the caregiving arena	Reports document and track trends in burden to parents in time, expense, career, etc. of parents of children with special needs.
17. Family Voices and www.familyvoices.org	Membership Brochure, web site	5, 11. 10, 11, 12, 17	Acknowledged caregivers	Makes the case for Families of children with special needs to band together
18. Kaiser Family Foundation	Booklet: Talking With Your Parents about Medicare and Health Coverage	9 – 12	Adult children of aging parents to discuss care options and how to pay for them	Addresses the possibility of providing home-based care as parents need more help, but all discussion is focused on needs of recipient, not of caregiver.
19. Lilit, the Independent Jewish Women's Magazine	Several articles on eldercare in three different issues	1-8, 13, 14, 16,	Acknowledged and unacknowledged caregivers	Designed to help caregivers self-identify, then address the issues
20. Muscular Dystrophy Association and www.mdaua.org	Web site brochure, "Taking Time Out for the Rest of Your Life"	8, 9, 11,13, 14, 16	Acknowledged caregivers	Emotionally supportive tone
21. National Alliance for Caregiving and www.caregiving.org	Web site brochure, "Tips for Caregivers" and web site	1 – 8, 9 –12, 13, 14, 16, 17	Acknowledged caregivers	Emotionally supportive tone
22. National Coalition for Cancer Survivors	"Cancer Survival Toolbox" (Series of six audiotapes, the sixth is titled "Caring for the Caregiver")	6 - 8, 9 – 12, 13 –1 4, 15, 16	Primarily for cancer survivors to pass on to their family caregivers	Emotionally supportive tone
23. National Family Caregivers Association and www.nfcacares.org	Brochures, "Share the Caring," "Choosing to Take Charge," "Defining the Help You Need," "10 Tips,"	1 – 17	Acknowledged and unacknowledged caregivers	Emotionally supportive tone

Organization	Item	Topics Covered (see codes, below table)	Target Audience	Comments
	various articles in <i>Take Care</i> newsletter, and web site			
24. National Health Council and www.nationalhealthcouncil.org	"Agenda for Action" (a position paper)	1-8	Policy makers, executives and program managers in the caregiving arena	Summarizes consensus of December 1998 conference on addressing caregiver issues
25. National Multiple Sclerosis Society and www.nationalmssociety.org	Web site brochure: A Guide for Caregivers	1-8, 9-12, 13, 14, 16	Acknowledged caregivers	Emotionally supportive tone
26. Nemours Foundation, www.Kidshealth.org web site	Web site brochure, "Stress Busters"	9-12, 13, 14, 16	Acknowledged parent caregiver of child with special needs	Practical tips for reducing stress
27. New Jersey Jewish News	<i>Elder Caregiving: An Exploration</i> (a 20-page special supplement)	1-16	Acknowledged and unacknowledged caregivers	Extensive, detailed information due to the length of the communications piece. Self ID is a minor topic; focus is more on dealing with the challenges as they present themselves.
28. U.S. Administration on Aging and www.AoA.gov	Fact Sheet, "Caregivers and Caregiving" and "Family Caregiver Fact Sheet"	1 – 8	Older people and their caregivers	Straight forward data and statistics
29. U.S. Administration on Aging	Web site brochure, "Because We Care: A Guide for People Who Care"	1, 2, 6-8, 9 –12, 13, 14, 16	Acknowledged caregivers	Practical tips and strategies
30. U.S. Department of Labor and www.dol.gov	Fact Sheet, "Work and Eldercare"	1, 2, 3, 4, 5, 8	Policy makers, executives and program managers in the caregiving arena	Emotionally supportive tone and practical tips for staying healthy and reducing stress
31. Virginia Institute for Developmental Disabilities, Virginia Commonwealth University	A Practical Guide to Respite for Your Family (a manual) and companion brochure "A Parent's Handbook for... Respite Care"	11, 15, 16	Acknowledged parent caregiver of child with special needs	Extensive detail on respite issues
32. Well Spouse Foundation and www.wellspouse.org	Membership brochure, "You are a well spouse when..." and web site	1, 2, 13, 14, 16	Acknowledged caregivers	General introduction to organization, provides a 9-point description to identify a "well spouse" Purpose is to drive membership, but in so doing it helps caregivers "self identify"
33. Well Spouse Foundation	"Mainstay" bi-monthly newsletters	1-14,16	Acknowledged caregivers	General support and encouragement for acknowledged caregivers/Well Spouse members
34. www.agenet.com	Web site	3, 5, 7, 8, 9 – 12, 16	The aging and their family caregivers and service providers	A network of products and services for the aging and those who care for them
35. www.caregiver.com	Web "magazine," solely devoted to caregiving issues	1, 2, 6, 7, 9 – 12, 13, 14, 16	Acknowledged caregivers	A network of products and services for family caregivers
36. www.care-givers.com	Web site solely devoted to caregiving issues	5-8,. 9 – 12, 15 – 17	Acknowledged caregivers	A network of products and services for family caregivers

Organization	Item	Topics Covered (see codes, below table)	Target Audience	Comments
37. www.caregiving.com	Web site solely devoted to caregiving issues	1 – 8, 9 – 12, 13, 14, 16	Acknowledged caregivers	A network of products and services for family caregivers of elders
38. www.caregiversadvisorypanel.com	Web site solely devoted to caregiving issues	1 – 14, 16	Acknowledged caregivers	Designed to conduct market research among caregivers
39. www.careguide.com	Web site solely devoted to caregiving issues	1-8, 9 –12, 13, 14, 16	Acknowledged caregivers and corporate HR/benefits managers	A web-based management company for caregiving services, developing a “Corporate Group Solutions” service
40. www.carescout.com	Web site solely devoted to caregiving issues	3, 5, 7, 8, 9 – 12, 16	Acknowledged caregivers	A web-based eldercare referral company
41. www.carethere.com	Web site solely devoted to caregiving issues	1 – 8, 9 – 12, 13, 14, 16	Acknowledged caregivers	A network of products and services for family caregivers
42. www.caregiverzone.com	Web site solely devoted to caregiving issues	1 – 8, 9 – 12, 13, 14, 16	Acknowledged caregivers	A network of products and services for family caregivers
43. www.ec-online.net (eldercare online)	Web site solely devoted to elder caregiving issues	6 – 8, 9 – 12, 13, 14, 15, 16	Acknowledged caregivers	A network of products and services for family caregivers of elders
44. www.familycareamerica.com	Web site solely devoted to caregiving issues	1, 2, 6, 7, 8, 9-12, 13, 14, 16	Acknowledged caregivers	A network of products and services for family caregivers
45. www.webofcare.com	Web site solely devoted to caregiving issues	6, 7, 8, 9 – 12, 16	Acknowledged caregivers	A network of products and services for family caregivers, and a separate portal for professional caregivers.

CODING FOR COMMUNICATIONS AUDIT

Topic areas are noted in the table by numbers as shown below.

General information:

1. Basic definitions of caregiving
2. Descriptions of caregiving tasks (including definitions or descriptions of Activities of Daily Living (ADLs) and Instrumental ADLs (IADLs))
3. Facts on the need for in-home caregiving as the population ages
4. Demographic data on caregivers
5. Trends in caregiving (gender, age, relationship to care recipient, intensity, work status, affect on work, “sandwich generation” issues, etc.)
6. Caregivers are not alone; they are part of a growing phenomenon.
7. The importance of educating oneself about the medical issues regarding the condition or disease the family member faces.
8. Additional sources for information: organizations, web sites, books, etc.

Specific skills or tasks:

9. Financial issues: paying bills, insurance coverage, Social Security and Medicare for an aging parent or spouse
10. How to hire paid home care
11. How to find and select respite care
12. How to interact with the health care team

Information that encourages caregivers to take care of themselves:

13. The importance of taking care of one’s own physical health: exercise, healthy diet, regular visits to health care provider.
14. Importance of taking care of mental and spiritual health: arrange respite, take time off, participate in enjoyable activities outside the caregiving situation

Information that helps unacknowledged caregivers acknowledge their situation and take action on their own behalf:

15. Encouragement to acknowledge the caregiving responsibility
16. Encouragement to “get help,” “take charge,” or “share” the caregiving
17. Encouragement to advocate on behalf of caregivers