

WHERE TO FIND HELP

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Caregiver Resource Center
Mount Sinai Medical Center
1425 Madison Avenue
East Building, Room L-4-89 (4th Floor)
New York, NY 10029
(212) 659-8989

Family Caregiver Alliance
690 Market Street, Suite 600
San Francisco, CA 94104
(800) 445-8106
(415) 434-3388
www.caregiver.org

Friend's Health Connection
P.O. Box 114
New Brunswick, NJ 08903
(800) 48-FRIEND (483-7436)
(732) 418-1811
www.48friend.org

Caregivers Service
Health Outreach Office
New York Presbyterian Hospital
525 East 68th Street, Box 143
New York, NY 10131
(212) 746-4365

National Alliance for Caregiving
4720 Montgomery Lane, Suite 642
Bethesda, MD 20814-3425
(301) 718-8444
www.caregiving.org

National Caregiving Foundation
801 North Pitt Street, #116
Alexandria, VA 22314
(800) 930-1357
(703) 299-9300
www.caregivingfoundation.org

National Family Caregivers Association
10400 Connecticut Avenue, Suite 500
Kensington, MD 20895
(800) 896-3650
(301) 942-6430
www.nfcacares.org

Rainbows
2100 Golf Road, #370
Rolling Meadows, IL 60008
(800) 266-3206
(847) 952-1770
www.rainbows.org

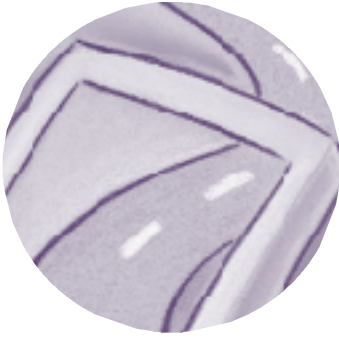
Rosalynn Carter Institute of Georgia Southwestern College
800 Wheatley Street
Americus, GA 31709
(912) 928-1234
rci.gsw.edu

The Compassionate Friends, Inc.
P.O. Box 3696
Oak Brook, IL 60522-3696
(630) 990-0010
www.compassionatefriends.org

Well Spouse Foundation
30 East 40th Street, PH
New York, NY 10016
(800) 838-0879
(212) 685-8815
www.wellspouse.org

To locate caregiver groups in your area, you can contact specific organizations listed by disease in Appendix B or ask a social worker.

APPENDIX B: ADVOCACY GROUPS BY DISEASE



AIDS/HIV

American Foundation for AIDS Research
120 Wall Street, 13th Floor
New York, NY 10005
(800) 39-amfAR (392-6327)
(212) 806-1600
www.amfar.org

HIV/AIDS Treatment Information Service
P.O. Box 6303
Rockville, MD 20849
(800) HIV-0440 (448-0440)
(301) 738-6616
www.hivatis.org

**Centers for Disease Control and Prevention
National HIV/AIDS Hotline**
(800) 342-AIDS
(800) 344-SIDA (Spanish)
(800) AIDS-889 (for the deaf/hearing-impaired)
www.cdc.gov

Gay Men's Health Crisis
119 West 24th Street
New York, NY 10011
(800) AIDS-NYC (243-7692)
(212) 807-6655
(212) 645-7470 (for the deaf/hearing-impaired)
www.gmhc.org

National Association of People with AIDS
1413 K Street, NW, 7th Floor
Washington, DC 20005
(202) 898-0414
www.napwa.org

ALZHEIMER'S DISEASE

Alzheimer's Association
919 North Michigan Avenue, Suite 1100
Chicago, IL 60611
(800) 272-3900
(312) 335-8700
www.alz.org

Alzheimer's Disease Education and Referral Service
The ADEAR Center
P.O. Box 8250
Silver Spring, MD 20907
(800) 438-4380
(301) 495-3311
www.alzheimers.org

ARTHRITIS

Arthritis Foundation
1650 Bluegrass Lakes Parkway
Alpharetta, GA 30004
(800) 283-7800
www.arthritis.org

AMYOTROPHIC LATERAL SCLEROSIS

The Amyotrophic Lateral Sclerosis Association
The ALS Association National Office
27001 Agoura Road, Suite 150
Calabasas Hills, CA 91301
(800) 782-4747
(818) 880-9007
www.alsa.org

BRAIN INJURY

Brain Injury Association
105 North Alfred Street
Alexandria, VA 22314
(800) 444-6443
(800) 228-8201 (within NY)
www.neurolaw.com
www.bianys.org

CANCER

American Cancer Society
1599 Clifton Road
Atlanta, GA 30329
(800) ACS-2345 (227-2345)
www.cancer.org

National Cancer Institute
Cancer Information Service
Building 31, Room 10A07
31 Center Drive MSC 2580
Bethesda, MD 20892
(800) 4-CANCER (422-6237)
www.cancer.gov

Cancer Care, Inc.
275 Seventh Avenue
New York, NY 10001
(800) 813-HOPE (outside the tri-state area)
(212) 302-2400
www.cancercareinc.org

CEREBRAL PALSY

United Cerebral Palsy Association
1600 L Street, NW, Suite 700
Washington, DC 20036
(800) USA-5-UCP (872-5827)
(202) 776-0406
www.ucpa.org

CHRONIC OBSTRUCTIVE PULMONARY DISEASE

American Lung Association
1740 Broadway
New York, NY 10019
(800) 586-4872
(212) 315-8700
www.lungusa.org

CYSTIC FIBROSIS

Cystic Fibrosis Foundation
6931 Arlington Road, Suite 200
Bethesda, MD 20814
(800) FIGHT CF (344-4823)
(301) 951-4422
www.cff.org

DIABETES

American Diabetes Association
1701 North Beauregard Street
Alexandria, VA 22311
(800) DIABETES (342-2383)
(703) 549-1500
www.diabetes.org

EPILEPSY

Epilepsy Foundation of America
4351 Garden City Drive
Landover, MD 20785
(800) EFA-1000 (332-1000)
(301) 459-3700
www.efa.org

HEART DISEASE AND STROKE

American Heart/Stroke Association
7272 Greenville Avenue
Dallas, TX 75231
(800) AHA-USA1 (242-8721) (Heart and Stroke Information)
(888) 4-STROKE (Stroke Information)
(888) MY HEART (Women's Health Information)
www.americanheart.org
www.strokeassociation.org

National Stroke Association
96 Inverness Drive East, Suite I
Englewood, CO, 80112
(800) 787-6537
(303) 649-9299
www.stroke.org



KIDNEY DISEASE

American Association of Kidney Patients

100 South Ashley Drive, Suite 280
Tampa, FL 33602
(800) 749-2257
www.aakp.org

American Kidney Fund

6110 Executive Boulevard, Suite 1010
Rockville, MD 20852
(800) 638-8299
(301) 881-3052
www.akfinc.org

The National Kidney Foundation

30 East 33rd Street, Suite 1100
New York, NY 10016
(800) 622-9010
(212) 889-2210
www.kidney.org

LIVER DISEASE

American Liver Foundation

75 Maiden Lane, Suite 603
New York, NY 10038
(800) GO LIVER (465-4837)
www.liverfoundation.org

MENTAL ILLNESS

American Psychiatric Association

1400 K Street, NW
Washington, DC 20005
(202) 682-6000
www.psych.org

American Psychological Association

750 First Street, NE
Washington, DC 20002-4242
(800) 374-2721
(202) 336-5500
www.apa.org

National Alliance for the Mentally Ill

Colonial Place Three
2107 Wilson Blvd., Suite 300
Arlington, VA 22201
(800) 950-NAMI (6264)
(703) 524-7600
www.nami.org

National Depressive and Manic Depressive Association

730 Franklin Street, Suite 501
Chicago, IL 60610
(800) 82-NDMDA (826-3632)
(312) 642-0049
www.ndmda.org

National Institute of Mental Health

NIMH Public Inquiries
6001 Executive Boulevard, Rm. 8184, MSC 9663
Bethesda, MD 20892
(800) 421-4211
(301) 443-4513
www.nimh.nih.gov

National Mental Health Association

1021 Prince Street
Alexandria, VA 22314
(800) 969-NMHA (6642)
(703) 684-7722
www.nmha.org

MULTIPLE SCLEROSIS

The National Multiple Sclerosis Society

733 Third Avenue
New York, NY 10017
(800) FIGHT-MS (344-4867)
www.nmss.org
www.msny.org

PAIN

American Chronic Pain Association

P.O. Box 850
Rocklin, CA 95677
(916) 632-0922
www.theacpa.org

American Pain Foundation

111 South Calvert Street, Suite 2700
Baltimore, MD 21202
www.painfoundation.org

PARALYSIS

Christopher Reeve Paralysis Foundation
500 Morris Avenue
Springfield, NJ 07081
(800) 225-0292
www.paralysis.org

Kent Waldrep National Paralysis Foundation
16415 Addison Road, Suite 550
Addison, TX 75001
(877) SCI-CURE (724-2873)
(972) 248-7100
www.kwnpf.org

National Spinal Cord Injury Hotline
2200 Kernan Drive
Baltimore, MD 21207
(800) 526-3456
www.scihotline.org

PARKINSON'S DISEASE

The American Parkinson Disease Association, Inc.
1250 Hylan Blvd., Suite 4B
Staten Island, NY 10305
(800) 223-2732
(718) 981-8001
www.apdaparkinson.com

National Parkinson Foundation, Inc.
Bob Hope Parkinson Research Center
1501 N.W. 9th Avenue
Bob Hope Road
Miami, Florida 33136
(800) 327-4545
(305) 547-6666
www.parkinson.org

RARE DISORDERS

National Organization for Rare Disorders (NORD)
P.O. Box 8923
New Fairfield, CT 06812
(800) 999-NORD (6673)
(203) 746-6518
www.rarediseases.org

SICKLE CELL DISEASE

Sickle Cell Advocates for Research and Empowerment, Inc.
P.O. Box 630127
Bronx, NY 10463
(718) 884-9670
www.defiers.com

Sickle Cell Disease Association of America, Inc.
National Headquarters
200 Corporate Pointe, Suite 495
Culver City California 90230
(800) 421-8453
(310) 216-6363
www.sicklecelldisease.org

VISUAL IMPAIRMENT

American Foundation for the Blind
11 Penn Plaza, Suite 300
New York, NY 10001
(800) AFB Line (232-5463)
(212) 502-7600
www.afb.org

The Lighthouse, Inc.
111 East 59th Street
New York, NY 10022
(800) 829-0500
(212) 821-9200
(212) 821-9713 (for the deaf/hearing-impaired)
www.lighthouse.org

APPENDIX C: FINANCIAL/LEGAL ASSISTANCE

FOR HEALTH CARE/MEDICATION

AIDS Drug Assistance Program

Centers for Disease Control and Prevention
National HIV/AIDS Hotline
(800) 342-AIDS (342-2437)
(800) 344-SIDA (Spanish)
(800) AIDS-889 (for the deaf/hearing-impaired)
- OR -

Call your state Department of Health:
(518) 459-1641 (New York State Department of Health)

American Association of Retired Persons (AARP)

601 E St., NW
Washington, DC 20049
(800) 424-3410
www.aarp.com

American Bar Association

Commission on Legal Problems of the Elderly
740 Fifteenth Street, NW, 8th Floor
Washington, DC 20005
(202) 662-1032
www.abanet.org/elderly

American Health Assistance Foundation

15825 Shady Grove Road, Suite 140
Rockville, MD 20850
(800) 437-2423
(301) 948-3244
www.ahaf.org

Directory of Prescription Drug Patient Assistance Programs

Pharmaceutical Research and Manufacturers of America (PhRMA)
1100 Fifteenth Street, NW
Washington, DC 20005
(800) 762-4636
(202) 835-3400
www.phrma.org/patients

Health Care Financing Administration

7500 Security Boulevard
Baltimore, MD 21244
(800) MEDICARE (633-4227)
(410) 786-3000
www.hcfa.gov (information about health care)
www.medicare.gov (Medicare information)

Hill-Burton Program

Health Resources and Services Administration
12300 Twinbrook, Suite 5200
Rockville, MD 20857
(800) 638-0742
(301) 443-5656
www.hrsa.dhhs.gov/osp/dfcr

Medicare Rights Center

(800) 333-4114
(212) 869-3850 (in New York City)
www.medicarerights.org

The Medicine Program

P. O. Box 515
Doniphan, MO 63935-0515
(573) 778-1118
www.themedicineprogram.com

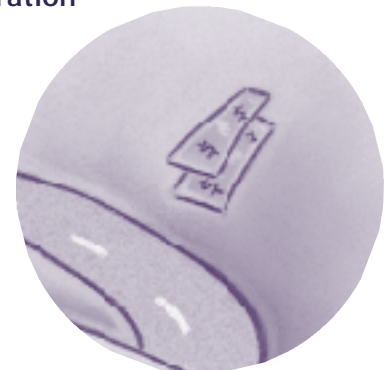
FOR PERSONAL FINANCES

Financial Planning Association

5775 Glenridge Drive, NE, Suite B-300
Atlanta, GA 30328
(800) 945-IAFP (4237)
(800) 282-7526
(404) 845-0011
www.fpanet.org

Social Security Administration

Toll-free Information Line
(800) 772-1213
www.ssa.gov



APPENDIX D: RESPITE CARE/VOLUNTEER SERVICES

American Red Cross
ARC in Greater New York
150 Amsterdam Ave
New York, NY 10023
(212) 787-1000
www.nyredcross.org

B'nai B'rith
1640 Rhode Island Avenue, NW
Washington, DC 20036
(202) 857-6600
bnaibrith.org

Catholic Charities USA
1731 King Street, Suite 200
Alexandria, VA 22314
(703) 549-1390
www.catholiccharitiesusa.org

Eldercare Locator
Administration on Aging
330 Independence Avenue, SW
Washington, DC 20201
(800) 677-1116
(202) 619-7501
www.aoa.gov

Elderserve
The Hebrew Home at Home
3260 Henry Hudson Parkway
Riverdale, NY 10463
(800) 567-3646
www.elderserve.org

**Family Friends (for children with disabilities
or chronic illness)**
National Council on Aging
Director of Intergenerational Programs
409 Third Street, SW, Second Floor
Washington, DC 20024
(202) 479-6675

Meals On Wheels Association of America
1414 Prince Street, Suite 202
Alexandria, Virginia 22314
(800) 999-6262
(703) 548-5558
www.mealsonwheelsasn.org

National Easter Seal Society
230 West Monroe Street, Suite 1800
Chicago, IL 60606
(800) 221-6827
(312) 726-6200
(312) 726-4258 (TTY)
www.easter-seals.org

**National Federation of Interfaith Volunteer
Caregivers, Inc.**
One West Armour Blvd, Suite 202
Kansas City, MO 64111
(800) 350-7438
(816) 931-5442
www.nfivc.org

National Respite Locator Service
ARCH National Resource Center
Chapel Hill Training-Outreach Project
800 Eastowne Drive, Suite 105
Chapel Hill, NC 27514
(800) 7-RELIEF (773-5433)
www.chtop.com/locator.htm

United Way of America
701 North Fairfax Street
Alexandria, VA 22314
(800) 411-8929
(703) 836-7112
www.unitedway.org

Volunteers of America
1660 Duke Street
Alexandria, VA 22314
(800) 899-0089
(703) 341-5000
www.voa.org

APPENDIX E: TRANSPORTATION



Access-A-Ride

MTA New York City Transit
Paratransit Division
Department of Buses
10 Columbus Circle, 17th Floor
New York, NY 10019
(212) 374-5634
(877) 337-2017 (reservations, applications, eligibility)
(212) 333-3147 (for the deaf/hearing-impaired)

American Red Cross

ARC in Greater New York
150 Amsterdam Ave
New York, NY 10023
(212) 787-1000
www.nyredcross.org

Eldercare Locator

Administration on Aging
330 Independence Avenue, SW
Washington, DC 20201
(800) 677-1116
www.aoa.gov

Health Care Financing Administration

(to determine coverage for transportation under Medicaid/Medicare)
7500 Security Boulevard
Baltimore, MD 21244
(800) MEDICARE (633-4227)
(410) 786-3000
www.hcfa.gov
www.medicare.gov (Medicare information)

State/City Departments for the Aging

New York State: 2 Empire State Plaza
Albany, NY 12223
(800) 342-9871 (Senior Citizens' Hot Line)
www.aging.state.ny.us
New York City: 2 Lafayette Street
New York, NY 10007
(212) 442-1000
www.ci.nyc.ny.us/html/dfta

Project Cart (New York City only)

490 Second Avenue
New York, NY 10016
(212) 221-3300

For additional transportation options check with associations related to specific diseases listed in Appendix B or volunteer organizations listed in Appendix D.



Hospice Foundation of America

2001 S St., NW #300
Washington, DC 20009
(800) 854-3402
www.hospicefoundation.org

National Association for Home Care

228 Seventh Street, SE
Washington, DC 20003
(202) 547-7424 (home care)
(202) 546-4759 (hospice)
www.nahc.org

American Health Care Association

1201 L St., NW
Washington, DC 20005
(202) 842-4444
www.ahca.org

National Hospice and Palliative Care Organization

1700 Diagonal Road, Suite 300
Alexandria, VA 22314
(800) 658-8898
(703) 243-5900
www.nhpco.org

Americans for Better Care of the Dying

2175 K Street, NW, Suite 820
Washington, DC 20037
(202) 530-9864
www.abcd-caring.com

Visiting Nurse Association of America

11 Beacon Street, Suite 910
Boston, MA 02108
(888) 866-8773
(617) 523-4042
www.vnaa.org

Choice in Dying/Partnership for Caring

1035 30th Street, NW
Washington, DC 20007
(800) 989-WILL (9455)
www.choices.org
www.partnershipforcaring.org

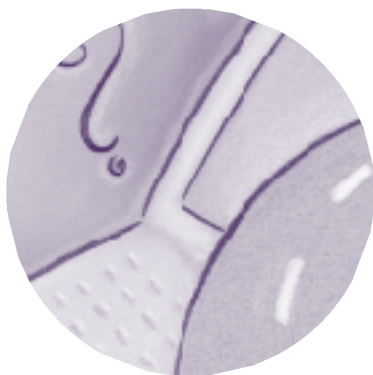
Elderserve

The Hebrew Home at Home
3260 Henry Hudson Parkway
Riverdale, NY 10463
(800) 567-3646
www.elderserve.org

Hospice Education Institute

190 Westbrook Road
Essex, CT 06426
(800) 331-1620 (Hospicelink)
(860) 767-1620
www.hospiceworld.org

APPENDIX G: CAREGIVER WEBSITES



AARP – American Association of Retired Persons

www.aarp.org/caregive/home.html

Caregiver-Information.com

www.caregiver-information.com

Caregiver Network, Inc.

www.caregiver.on.ca

Caregiver Survival Resources

www.caregiver911.com

Caregiver Zone – The Site for Caregivers and Seniors

caregiverzone.com

Caregivers.com

www.caregivers.com

Caregiving.com

www.caregiving.com

Careguide.com

www.careguide.com

CareThere.com

www.carethere.com

Thirddage.com - Caregiving

www.thirddage.com/family/caregiving

Eldercare Online

www.ec-online.net

Empowering Caregivers

www.care-givers.com

Familycare America

www.familycareamerica.com

Family Caregivers Alliance

www.caregiver.org

Friend's Health Connection

www.48friend.org

Healthy Caregiver.com

www.healthycaregiver.com

National Alliance for Caregivers

www.caregiving.org

National Family Caregivers Association

www.nfcacares.org

National Partnership for Women and Families

www.nationalpartnership.org

Resources for Caregivers

www.abs.sdstate.edu/ae/agrability/care/resources.html

Rosalynn Carter Institute of Georgia Southwestern College

rci.gsw.edu

The Caregiver Guide – Resource Links

www.rbs4u.com/caregiver/links.htm

Today's Caregiver Magazine Online

www.caregiver.com

U.S. Administration on Aging – Caregiver Resources

<http://www.aoa.dhhs.gov/caregivers/default.htm>

Web Of Care

www.webofcare.com/home.html

Well Spouse Foundation

www.wellspouse.org

APPENDIX H: CAREGIVER BOOKS/GUIDES



- American Cancer Society. *Caring for the Patient with Cancer at Home: A Guide for Patients and Families*. Atlanta: American Cancer Society, 1998.
- Beedle, Joyce & Dunn, Louise (Editors). *The Carebook: A Workbook for Caregiver Peace of Mind*. Portland, Oregon: Lady Bug Press, 1991.
- Berman, Claire. *Caring for Yourself While Caring for Your Aging Parents: How to Help, How to Survive*. New York: Henry Holt & Company, 1996.
- Brammer, Lawrence & Bingea, Marian. *Caring for Yourself While Caring for Others: A Caregiver's Survival and Renewal Guide*. New York: Vantage Press, 1999.
- Brandt, Avrene. *Caregiver's Reprieve: A Guide to Emotional Survival When You're Caring for Someone You Love (The Working Caregiver Series)*. San Luis Obispo, California: Impact Publishers, 1997.
- Cancer Care. *A Helping Hand: The Resource Guide for People with Cancer*. New York: Cancer Care, Incorporated, 1996.
- Dolan, Michael. *How to Care for Your Aging Parents...and Still Have a Life of Your Own!* Los Angeles: Mulholland Pacific, 1992.
- Hereema, Carol. *A Caregiver's Guide to Giving Medicines*. Upper Saddle River, New Jersey: Prentice Hall, 1999.
- Houts, Peter. *American College of Physicians Home Care Guide for Cancer: For Family and Friends Giving Care at Home*. Philadelphia: American College of Physicians, 1994.
- Ilardo, Joseph & Rothman, Carole. *I'll Take Care of You: A Practical Guide for Family Caregivers*. Oakland, California: New Harbinger, 1999.
- Levine, Carol, (Ed.) *Always on Call: When Illness Turns Families into Caregivers*. New York: United Hospital Fund, 2000.
- Lipsyte, Robert. *In the Country of Illness: Comfort and Advice for the Journey*. New York: Alfred A. Knopf, 1998.
- McFarlane, Rodger & Bashe, Philip. *The Complete Bedside Companion: A No-Nonsense Guide to Caring for the Seriously Ill*. New York: Fireside, 1999.
- McGonigle, Chris. *Surviving Your Spouse's Chronic Illness: A Compassionate Guide*. New York: Henry Holt & Company, Incorporated, 1999.
- Meyer, Maria, Derr, Paula, & Hatfield, Mark. *The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers*. Portland, Oregon: CareTrust Publications, 1998.
- National Family Caregivers Association. *The Resourceful Caregiver: Helping Family Caregivers Help Themselves*. St. Louis, Missouri: Mosby, 1996.
- Olshevski, Jodi, Katz, Anne, & Knight, Bob. *Stress Reduction for Caregivers*. Philadelphia: Brunner/Mazel, 1999.
- Ortho Biotech. *Strength for Caring: Education and Support for Family Cancer Caregivers*. Raritan, New Jersey: Ortho Biotech, Inc., 1998.
- Schonhoff, Shelly & Speaker, Joanna. *Family Caregiver Guide: A Comprehensive Handbook for Caring for Your Loved One at Home*. Dubuque, Iowa: Simon & Kolz Publishing, 1998.
- Unger, James A. *From Caregiver to Caregiver: How to Cope*. Lima, Ohio: CSS Publishing Company, 1995.
- Visiting Nurse Associations of America. *Caregiver's Handbook: A Complete Guide to Home Health Care*. New York: DK Publishing, 1998.