

## General Caregiver Resources

Credit to the Department of Pain, Medicine and Palliative Care of Beth Israel Medical Center, NYC. This list, as well as other excellent caregiver information, can be found on their website [www.netofcare.org](http://www.netofcare.org). We have added brief descriptions of each resource.

### Listed by Illness

#### Alzheimer's Disease

##### Alzheimer's Association

[www.alz.org](http://www.alz.org) / [www.alznyc.org](http://www.alznyc.org)

800-272-3900 (24 hour helpline)

212-983-0700 (NYC Chapter)

Legal services, evaluation, support groups, workshops

##### Alzheimer's Disease Education and Referral Service

[www.alzheimers.org](http://www.alzheimers.org)

800-438-4380

Compile, archive, and disseminate information concerning Alzheimer's disease. Answer questions, make referrals, and provide free publications.

#### Arthritis

[www.arthritis.org](http://www.arthritis.org)

800-568-4045 (for related information and materials)

800-283-7800 (to order materials, make donations)

212-984-8700 (NY Chapter)

Free booklets, trainings for new instructors, self-help, support group, trainings, answer questions, send out materials, support research

## **Amyotrophic Lateral Sclerosis**

www.alsa.org

800-782-4747 (patient services)

212-619-1400 (NY Chapter)

Support groups, equipment loan programs, booklets, materials, videos, information, clinics, referral list, advocacy, research program

## **Brain Injury**

*Brain Injury Association of America*

www.biausa.org

800-444-6443

800-228-8201 (NY State)

518-459-7911

Support groups, send out publication packet, resource specialist, family advocate for children

## **Cancer**

*CancerCare*

www.cancercare.org

800-813-HOPE (4673)

212-712-8080

Financial aid; Free counseling

*American Cancer Society*

www.cancer.org

800-ACS-2345 (227-2345)

*National Cancer Institute*

www.cancer.gov

http://cancernet.nci.nih.gov/

800-4-CANCER (800-422-6237)

Referral services to support groups and information

*The National Coalition for Cancer Survivorship*

[www.canceradvocacy.org](http://www.canceradvocacy.org)

877-NCCS-YES (877-622-7937) – to order materials

1-888-650-9127 – for general information

1-301-650-9127

Free patient resources and publications on health insurance, employment rights, talking with doctor, and living with hope. In addition, the organization also provides Cancer Survival Toolbox® and audio-programs to help people with cancer to develop communication and decision making skills.

*OncoLink*

[oncolink.upenn.edu/coping/index.cfm](http://oncolink.upenn.edu/coping/index.cfm)

Information for caregivers and patients

## **Cerebral Palsy**

*United Cerebral Palsy Association*

[www.ucp.org](http://www.ucp.org) / <http://www.ucpnyc.org/>

800-872-5827

212-979-9700 ext. 720 (central information and referral, UCP of NYC)

## **Chronic Obstructive Pulmonary Disease**

*American Lung Association*

[www.lungusa.org](http://www.lungusa.org)

800-586-4872

Literature and information

## **Cystic Fibrosis**

*Cystic Fibrosis Foundation*

[www.cff.org /](http://www.cff.org/)

[http://www.cff.org/living\\_with\\_cf/patient\\_and\\_family\\_education/](http://www.cff.org/living_with_cf/patient_and_family_education/)

800 FIGHT CF (344-4823)  
301 951 4422  
Help research, not individuals  
Provide some information online

## **Diabetes**

*American Diabetes Association*

[www.diabetes.org](http://www.diabetes.org)

800-DIABETES (800-342-2383)

Information about diabetes, parenting and family life

## **Epilepsy**

*Epilepsy Foundation of America*

[www.epilepsyfoundation.org/](http://www.epilepsyfoundation.org/)

800 EFA 1000 (344-4823)

301-951-4422

Information for patient and family

## **Heart Disease and Stroke**

*American Heart/Stroke Association*

[www.americanheart.org](http://www.americanheart.org)

[www.strokeassociation.org](http://www.strokeassociation.org)

800-242-8721

888-4-STROKE (888-478-7653)

Provide resources for support groups and other information

*National Stroke Association*

[www.stroke.org](http://www.stroke.org)

800-787-6537

303-649-9299

## **Kidney Disease**

### American Association of Kidney Patients

[www.aakp.org](http://www.aakp.org)

800-749-2257

### American Kidney Fund

[www.akfinc.org](http://www.akfinc.org)

800-638-8299 (help line)

### The National Kidney Foundation

[www.kidney.org](http://www.kidney.org)

800-622-9010

212-889-2210

## **Liver Disease**

[www.liverfoundation.org](http://www.liverfoundation.org)

800 GO LIVER (800-465-4837)

888 4HEP USA (888-443-7872)

2121-668-1000

## **Mental Illness**

### American Psychiatric Association

[www.psych.org](http://www.psych.org) / <http://www.healthyminds.org/>

888-35-PSYCH

### American Psychological Association

[www.apa.org](http://www.apa.org)

800-374-2721

### National Alliance for the Mentally Ill

[www.nami.org](http://www.nami.org)

800-950-NAMI (6264) (information helpline)

703-524-7600

National Depressive and Manic Depression Association

[www.ndmda.org](http://www.ndmda.org)

800-826-3632

312-642-0049

National Institute of Mental Health

[www.nimh.nih.gov](http://www.nimh.nih.gov)

866-615-6464

301-443-4513

National Mental Health Association

[www.nmha.org](http://www.nmha.org)

800-969-NMHA (6642)

703-684-7722

## Multiple Sclerosis

National Multiple Sclerosis Society

[www.nmss.org](http://www.nmss.org)

[www.msny.org](http://www.msny.org)

800-FIGHT-MS (800-344-4867)

## Pain

American Chronic Pain Association

[www.theacpa.org](http://www.theacpa.org)

800-533-3231

American Pain Foundation

[www.painfoundation.org](http://www.painfoundation.org)

888-615-PAIN (7246)

## **Paralysis**

*Christopher Reeve Paralysis Foundation*

[www.paralysis.org](http://www.paralysis.org)

800-539-7309

*National Spinal Cord Injury Association*

[www.spinalcord.org](http://www.spinalcord.org)

800-962-9629

## **Parkinson's Disease**

*The American Parkinson Disease Association, Inc.*

[www.apdaparkinson.org](http://www.apdaparkinson.org)

800-223-2732

*National Parkinson Foundation*

[www.parkinson.org](http://www.parkinson.org)

800-327-4545

Can search for support group or local resources

## **Rare Disorders**

*National Organization for Rare Disorders (NORD)*

[www.rarediseases.org](http://www.rarediseases.org)

800-999-6673

203-744-0100

## **Visual Impairment**

*American Foundation for the Blind*

[www.afb.org](http://www.afb.org)

800-AFB-LINE (800-232-5463)

212-502-7600

The Lighthouse, Inc.  
www.lighthouse.org  
800-829-0500  
212-821-9200

## Resource Centers/Advocacy Groups--National

### Caregiver Resource Center

Mount Sinai Medical Center  
1425 Madison Avenue  
East Building, Room L-4-89 (4<sup>th</sup> Floor)  
New York, NY 10029  
212-659-8989  
www.mountsinai.org/capp

Caregivers and professional partnership provides information assistance and referral services, support group for adults and children of Alzheimer's Disease, offer support and counseling (online and over telephone), limited funding to assist with minimal caregiver items.

### Family Caregiver Alliance

690 Market Street, Suite 600  
San Francisco, CA 94104  
800-445-8106 (leave voice message, no live answer)  
www.caregiver.org

Offer caregiving information, advice, fact sheets, online resources

### Friend's Health Connection

PO Box 114  
New Brunswick, NJ 08903  
800-48-FRIEND (483)  
732-418-1811

www.friendshealthconnection.org

Nonprofit organization that offers networking and communication opportunities for participants, family members, friends and

caregivers of people with health problems. The organization connects caregiver and patients to each other depending on detailed personal profile and send out matches. People who are matched in the same group can decide how to further establish contact (i.e. get food or talk over the phone). The organization also provides events around New Jersey and New York to educate the public about well-being. Participants can also sign up for a pen pal online for free and establish international network.

Caregivers Service

Health Outreach Office  
New York Presbyterian Hospital  
525 East 68<sup>th</sup> Street, Box 143  
New York, NY 10131  
212-746-4365

Offers individual counseling and support group, caregivers have to be caring for someone over 60 years old.

National Alliance for Caregiving

4720 Montgomery Lane, Suite 642  
Bethesda, MD 2814-3425  
301-718-8444

[www.caregiving.org](http://www.caregiving.org)

Provide reports, guides, publication, and tips for caregivers. Conduct research and public policy, develop brochures available on website for the public (two publications sections online: research reports and consumers.) Partner with national family caregiving services to create: [www.Familycaregiving101.org](http://www.Familycaregiving101.org)

National Caregiving Foundation

801 North Pitt Street, #116  
Alexandria, VA 22314  
800-930-1357 (to order a kit)  
703-299-9300 (to reach an office personnel)  
[www.caregivingfoundation.org](http://www.caregivingfoundation.org)

Nonprofit organization that provides free *Caregiver's Support Kit*<sup>®</sup> (include educational material and guideline for coping) for patients and caregivers affected by Alzheimer's Disease, has a small assisted living facility in Maryland (currently 6 residents.)

*National Family Caregivers Association*

10400 Connecticut Avenue, Suite 500

Kensington, MD 20895

800-896-3650

301-942-6430

[www.thefamilycaregiver.org](http://www.thefamilycaregiver.org)

Provides educational resources, tips, newsletter about caregivers, read and share stories about caregiving. Focus on common issue experiences, information and support through mail, free membership.

*Rainbows*

2100 Golf Road, #370

Rolling Meadows, IL 60008

800-266-3206 (call for sites near you)

847-952-1770

[www.rainbows.org](http://www.rainbows.org)

Fosters emotional healing among children grieving a loss from a life-altering crisis. International sites (at school and churches), provide grief support groups for children for free in all states of US, children meet in small groups once a week for 14 weeks

*The Compassionate Friends, Inc.*

PO Box 3696

Oak Brook, IL 60522-3696

630-990-0010

877-969-0010 (toll free)

[www.compassionatefriends.org](http://www.compassionatefriends.org)

Nation-wide assistance to families toward the positive resolution of grief following the death of a child for any age and cause, provide

information to help others be supportive, provide in person and telephone support.

*Well Spouse Foundation*

30 East 40<sup>th</sup> Street, PH

New York, NY 10016

800-838-0879

732-577-8899

[www.wellspouse.org](http://www.wellspouse.org)

Support wives, husbands, and partners of the chronically ill and/or disabled. Small membership fee \$25/year, provide support groups only for spouse, sends out quarterly newsletters, national conference once a year.