

Patient Support Networks: Something for Everyone

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With the emphasis of American health care shifting toward patient rights and education, the resources available through patient support networks are a valuable supplement to physician services. Support networks are groups organized around specific conditions or disorders, their diagnosis, treatment, and prevention. As with other forms of patient education, support networks enable patients to become more in-

formed about their disease and to play a more active role in their health care. Following a summary of patient-physician-support network relationships and the benefits thereof, a list of patient support resources is provided.

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They are multiplying like Texas bluebonnets in spring: support networks for patients. In this period of transition for American health care in which the emphasis has shifted to patient rights and education, resources from patient support networks are a valuable supplement to the physician's services. As with other forms of patient education, support networks can help patients become more informed about their health and take a more active role in their health care.

For years I have collected telephone numbers of local and national support groups, writing them into my "little black book" alongside the telephone numbers of colleagues and favorite restaurants. Only recently did I assemble the patient support groups into one list for easier access. My initial list of 20 or so rapidly expanded as I began to seek out resources for a more complete list. Organizations emerged from many sources: medical journals, lay magazines (particularly those for women), newspaper columns devoted to support groups and meeting dates, and patients.

What Is a Support Network?

A support network is a group of people devoted to promoting the proper diagnosis, treatment, and prevention of a specific condition, primarily through patient education and support. Additional emphasis is placed on non-medicinal treatment, such as nutrition, physical fitness, and stress management. Usually formed and managed by people who have the disease or by the family members of people who have the disease, support networks provide varying services, including:

- Written information in the form of newsletters, brochures, and medical articles
- Updates on the latest in medical research with regard to disease diagnosis, management, and prevention
- A list of local support groups that provide a means to share knowledge, ideas, and emotional support with other patients.

Family physicians are particularly well suited to using support networks in patient care settings, since our specialty has its foundation in our ability to see patients not as disease entities but as persons with many dimensions and interpersonal relationships. In my experience, I refer, or "plug in," patients to support networks far more often than do the specialists whom my patients see. Many years ago, on arriving in a new city to practice medicine, I tried to locate the area Alzheimer's support group. After calling the offices of three neurologists, none of whom knew

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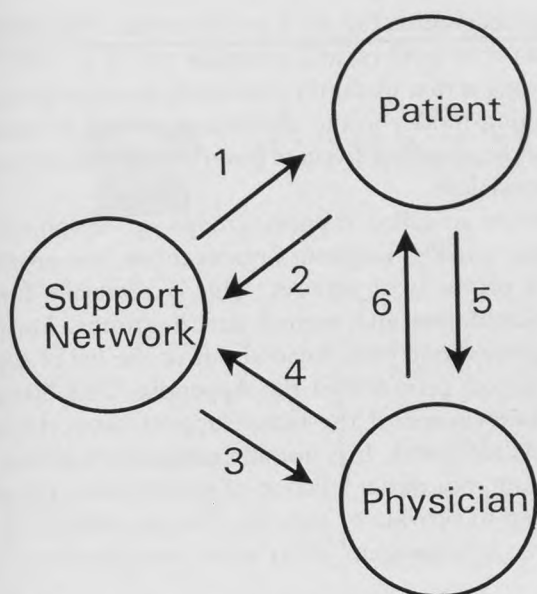


Figure. Multidimensional relationship among support network, patient, and physician.

about such a group, I contacted a social worker at the Catholic hospital, who provided the information I was looking for. When I called the Alzheimer's disease group coordinator, she was surprised and very happy that a *physician* was actually interested in their work!

Characteristics of Support Networks

Aside from the common goals listed above, support networks are tremendously varied in their structure and organization. Many are large and well known, such as the American Cancer Society and the Alzheimer's Foundation. Others are "kitchen table" organizations: small in size but large in commitment and enthusiasm. When one calls a network on the telephone, the person who answers may be in a large office building or at home. In addition to varying in size, support networks also operate on a wide range of budgets. The impact this variation has on patients is that some networks provide educational material, such as newsletters and brochures, at no cost to the patient, while others charge a fee.

A Healthful Trio

As in any relationship, the association between physician, patient, and support network has many dimensions (Figure).

1. SUPPORT NETWORK → PATIENT

Support networks provide to patients a multitude of resources, broadly classified as educational and emotional

support. Fliers, audio and videotapes, newsletters, medical articles, and lectures provide the patient and family with information that is not always available at the physician's office. In addition, support group members encourage discussion among people with a similar disease, reassuring patients that they are not alone or unique. Many people find it easier to divulge feelings and problems to people outside the emotion-laden setting of the family, and can learn from solutions others have found to similar difficulties.

2. PATIENT → SUPPORT NETWORK

Many patients or family members, in return, share their talents and knowledge by becoming part of the support network organization. Their involvement often helps them look beyond their own problems and reach out to others: helping other people becomes their own therapy.

3. SUPPORT NETWORK → PHYSICIAN

The physician who makes use of support networks will discover an extraordinary array of resources, often available at no cost. In addition to the benefit of having a patient who is more educated about his or her disease and more motivated to treat it appropriately, the physician can obtain a variety of patient handouts to use in the office. Physicians may choose to have their names or practices added to the mailing lists of certain support networks. Liaison between the physician and the support network facilitates patient referrals to physicians who are interested in or have expertise in a particular disease or condition.

4. PHYSICIAN → SUPPORT NETWORK

The support networks I have contacted have been happy to find an ally for their "cause" in the medical community. Interested physicians are invited to attend support group meetings to share their expertise with the community. I often send articles from medical journals to local support networks to update them on news from the medical front and to communicate my continuing interest.

5. PATIENT → PHYSICIAN

A patient can share with his or her physician information learned through a support network with regard to the latest discoveries and theories about the disease. This enhances the "partnership" model of the patient-physician relationship and improves the medical care provided to that patient as well as to others with the same condition.

6. PHYSICIAN → PATIENT

When physicians refer patients to support networks, they are demonstrating their perception of patients not merely

as diseases, but as persons for whom they want the best possible care and resources. Referral to a support network acts to strengthen the patient-physician relationship, which is so deeply valued by family physicians.

Caveat Medicus

- When referring a patient to a support group, I briefly explain what to expect. Some people think of support groups as consisting only of meetings in which group members share feelings and experiences, and therefore do not care to take part in them. To avoid this misperception, I inform the patient of the varied services that the support group may have to offer, such as newsletters, research updates, and lectures by health professionals. Since the needs and personality of each patient vary, the referring physician should recommend that patients investigate for themselves to see if a particular resource meets their needs.
- Unfortunately, some support groups encourage members to seek subspecialty care: eg, the person with diabetes should be managed by an endocrinologist, patients with osteoarthritis by a rheumatologist, members of asthma groups by a pulmonologist. While in the audience of an infertility support group meeting, I once heard the speaker tell the group that every infertile patient should be evaluated not by a

gynecologist, but by a gynecologist with a subspecialty in fertility, and *certainly* not by a "GP." The irony is that we family physicians are capable of managing most chronic illnesses, and with a sensitivity and comprehensiveness often not displayed by other specialists.

- Some so-called support groups or "helplines" are not actually nonprofit organizations, but promoters of products or services. This is especially true for weight loss and mental health groups. For-profit groups have been weeded out of the list of support services provided in the Appendix. This listing includes some of the many support networks in the United States. It is not an endorsement of any program, but rather a listing of resources for the physician to provide to patients. I hope readers will find that it helps them better serve their patients.

The doctor of the future will give no medicine, but will interest his patients in the care of the human frame, in diet, and in the cause and prevention of disease.

—Thomas Alva Edison

Acknowledgment

I would like to acknowledge the assistance and support of my mother, Betty Blum, in preparing this list of support networks.

Appendix



PATIENT INFORMATION NETWORKS

Disease/Condition	Organization	Phone Number
Abuse	Childhelp National Child Abuse Hotline	1-800-422-4453
	National Center for Kids in Crisis	1-800-334-4KID
	National Center for Missing & Exploited Children	1-800-843-5678
	National Committee to Prevent Child Abuse	1-800-CHILDREN
	National Resource Center on Child Sexual Abuse	1-800-KIDS-006
	National Resource Center on Domestic Violence	1-800-537-2238
Adoption	Adopt a Special Kid-America (AASK)	1-510-451-1748
	Adoptive Families of America	1-612-535-4829
AIDS	CDC National AIDS Hotline	1-800-342-AIDS 1-800-344-7432 (Spanish)
Alcoholism	Alcoholics Anonymous	1-212-870-3400
	Al-Anon & Al-Atcen Family Groups	1-800-356-9996
	American Council on Alcoholism	1-800-527-5344
	Children of Alcoholics Foundation	1-800-359-COAF
	Co-dependents Anonymous	1-212-685-3002
	National Organization on Fetal Alcohol Syndrome	1-800-66-NO-FAS
Allergies	American Association of Allergy & Immunology	1-800-822-ASMA
	Asthma & Allergy Foundation of America	1-800-7-ASTHMA
	National Allergy & Asthma Network	1-703-385-4403
Alopecia areata	National Alopecia Areata Foundation	1-415-456-4644
Alzheimer's disease (see also Caregivers)	Alzheimer's Family Care	1-800-600-1600
	Alzheimer's Foundation	1-800-272-3900
Amputation	National Amputation Foundation	1-516-887-3600
Anxiety (see also Mental illness)	Anxiety Disorders Association of America	1-301-231-9350
	Agoraphobics in Motion (AIM)	1-810-547-0400
	Freedom from Fear	1-718-351-1717
	NIMH Panic Disorder Information Line	1-800-64-PANIC
Aplastic anemia	Aplastic Anemia Foundation of America	1-800-747-2820
Arthritis	American Juvenile Arthritis Organization	1-404-872-7100
	Arthritis Foundation	1-800-284-2438
	National Arthritis Clearinghouse	1-301-495-4484
Asthma	Asthma & Allergy Foundation of America	1-800-7-ASTHMA
	Asthma Explorers—ages 6-12	1-800-982-3902
	National Allergy & Asthma Network	1-703-385-4403
Attention deficit disorder (see also Learning disability)	Children & Adults with ADD (CHADD)	1-800-233-4050
Autism	Autism Society of America	1-301-657-0881
Bladder cancer (see also Cancer)	American Foundation of Urologic Disease	1-800-242-2383
Brain tumor (see also Cancer)	American Brain Tumor Association	1-800-886-2282
	National Brain Tumor Foundation	1-800-934-CURE
Breast cancer (see also Cancer)	Reach to Recovery (mastectomy patients)	1-800-ACS-2345
	Y-Me National Breast Cancer Organization	1-800-221-2141
Breastfeeding	La Leche League	1-800-LA-LECHE

Cancer (see also specific types of cancer)	American Cancer Society Candlelighters Childhood Cancer Foundation National Cancer Institute	1-800-ACS-2345 1-800-366-2223 1-800-4-CANCER
Caregivers	National Council on Aging Children of Aging Parents Well Spouse Foundation	1-202-479-1200 1-215-945-6900 1-800-838-0879
Carpal tunnel syndrome	Association for Repetitive Motion Syndrome	1-707-571-0397
Celiac sprue	Celiac Sprue Association—USA	1-402-558-0600
Cerebral palsy	United Cerebral Palsy Associations	1-800-USA-5UCP
Chronic fatigue syndrome	Chronic Fatigue & Immune Dysfunction Syndrome Association	1-800-442-3437
Colitis	Crohns & Colitis Foundation	1-800-932-2423
Connective tissue disease	Coalition for Heritable Diseases of Connective Tissue	1-516-883-8712
Craniofacial disorders	Children's Craniofacial Association Cleft Palate Foundation	1-800-535-3643 1-800-24-CLEFT
Cystic fibrosis	Cystic Fibrosis Foundation	1-800-FIGHT-CF
Death	Aiding Mothers & Fathers Exploring Neonatal Death (AMEND) Compassionate Friends (bereaved parents) Grief Recovery Helpline SHARE Pregnancy & Infant Loss Support Widowed Persons Service	1-314-487-7582 1-708-990-0010 1-800-445-4808 1-314-947-6164 1-202-434-2260
Dental health/disease	Dental Health Foundation	1-415-499-4648
Depression (see also Mental Illness)	National Depressive & Manic Depressive Association National Foundation for Depressive Illness Recovery, Inc.	1-312-642-0049 1-800-248-4344 1-312-337-5661
Diabetes	American Assoc of Diabetic Educators American Diabetes Association Juvenile Diabetes Foundation	1-800-338-DMED 1-800-232-3472 1-800-JDF-CURE
Disability	Association for Persons with Severe Handicaps National Foundation of Dentistry for the Handicapped National Information Center for Children & Youth with Disabilities National Sports Center for the Disabled Special Olympics International	1-410-828-8274 1-303-298-9650 1-800-695-0285 1-303-726-5514 1-202-628-3630
Down syndrome	National Down Syndrome Congress National Down Syndrome Society	1-800-232-NDSC 1-800-221-4602
Drug abuse	Narcotics Anonymous	1-212-929-6262
Eating disorders	American Anorexia/Bulimia Association National Association of Anorexia Nervosa	1-212-501-8351 1-708-831-3438
Eczema	Eczema Association	1-503-228-4430
Emphysema/COPD	American Lung Association	1-800-LUNG-USA
Endometriosis	Endometriosis Association	1-800-992-ENDO
Epilepsy	Epilepsy Foundation of America National Institute of Neurological Disorders	1-800-EFA-1000 1-800-352-9424
Familial polyposis	Familial Polyposis Registry	1-800-998-4785

Family/parenting	America Belongs to Our Children (drug use prevention) American Academy of Family Practice American Academy of Pediatrics Children's Television Resource Center Focus on the Family Immunization Action Coalition National Maternal & Child Health Clearinghouse New Parents Network Parents Anonymous Toughlove International	1-800-783-6396 1-800-274-2237 1-800-433-9016 1-415-243-9943 1-800-A-FAMILY 1-612-647-9009 1-703-821-8955 1-602-327-1451 1-909-621-6184 1-800-333-1069
Fibromyalgia	Fibromyalgia Network Arthritis Foundation	1-800-853-2929 1-800-284-2438
Fitness	American Heart Association American Running & Fitness Association National Association for Sport & Physical Education Women's Sports Foundation	1-800-AHA-USA-1 1-301-913-9517 1-703-476-3410 1-800-227-3988
Food allergies	Food Allergy Network	1-800-929-4040
Gambling, compulsive	Council for Compulsive Gambling	1-800-742-0443
Genetic disease	Alliance of Genetic Support Groups Hereditary Disease Foundation	1-800-336-GENE 1-310-458-4183
Group B Strep, perinatal	Group B Strep Association	1-919-932-5344
Headaches	National Headache Foundation	1-800-843-2256
Head injury	National Head Injury Foundation	1-800-444-NHIF
Hearing impairment	American Society for Deaf Children Beginnings: Parents of Hearing Impaired Children Better Hearing Institute Helpline National Association for the Deaf Registry of Interpreters for the Deaf	1-800-942-ASDC 1-800-541-HEAR (voice/TTY) 1-800-EAR-WELL 1-301-587-1789 (TTY) 1-301-608-0050 (v/TTY)
Heart disease	American College of Cardiology American Heart Association	1-800-253-4636 1-800-AHA-USA-1
Heart surgery	Mended Hearts	1-800-AHA-USA-1
Hemophilia	National Hemophilia Foundation	1-212-219-8180
Hepatitis (see also Liver disease)	Hepatitis B Coalition	1-612-647-9009
Herpes	Herpes Hotline	1-800-230-6039
Homeless (see also Poverty)	National Coalition for the Homeless National Resource Center on Homelessness & Mental Illness	1-202-775-1322 1-800-444-7415
Hospice	National Hospice Organization Helpline	1-800-658-8898
Huntington's disease	Huntington's Disease Society of America	1-800-345-HDSA
Hydrocephalus	National Hydrocephalus Foundation	1-815-467-6548
Hypertension	American Heart Association National Heart, Lung, & Blood Institute	1-800-AHA-USA-1 1-800-575-WELL
Illiteracy	National Literacy Hotline	1-800-228-8813
Infertility	National Resolve Helpline	1-617-623-0744
Interstitial cystitis	Interstitial Cystitis Association of America	1-800-ICA-1626
Iron overload	Iron Overload Diseases Association	1-407-840-8512
Kidney disease	American Kidney Association National Kidney Foundation	1-800-638-8299 1-800-622-9010

Laryngeal cancer (see also Cancer)	International Association of Laryngectomees	1-404-320-3333
Learning disability	National Center for Learning Disabilities National Information Center for Children & Youth with Disabilities Orton Dyslexia Society	1-212-545-7510 1-800-695-0285 1-800-ABCD-123
Leukemia	Leukemia Society of America	1-800-683-2458
Liver disease	American Liver Foundation	1-800-223-0179
Lung disease	American Lung Association	1-800-LUNG-USA
Lupus	American Lupus Society Lupus Foundation	1-800-331-1802 1-800-558-0121
Lyme disease	Lyme Disease Foundation	1-800-886-LYME
Lymphedema	National Lymphedema Network	1-800-628-7672
Macular degeneration (see also Vision impairment)	Association for Macular Diseases	1-212-605-3719
Manic depressive illness (see also Mental illness)	National Depressive & Manic Depressive Association	1-312-642-0049
Mental illness	American Psychiatric Association Emotions Anonymous National Mental Health Association National Mental Health Consumer Self-Help Clearinghouse Recovery, Inc.	1-202-682-6220 1-612-647-9712 1-800-969-NMHA 1-800-553-4539 1-312-337-5661
Mental retardation	American Association on Mental Retardation Association for Retarded Citizens Mental Retardation Association of America National Apostolate with People with Ment Ret	1-800-424-3688 1-800-433-5255 1-801-328-1575 1-800-736-1280
Mitral valve prolapse	MVP/Dysautonomia Foundation	1-800-541-8602
Multiple sclerosis	Multiple Sclerosis Association of America Multiple Sclerosis Society	1-800-833-4672 1-800-LEARN-MS
Muscular dystrophy	Muscular Dystrophy Association	1-800-572-1717
Myasthenia gravis	Myasthenia Gravis Foundation	1-800-541-5454
Neurologic disease	National Institute of Neurological Disorders	1-800-352-9424
Neurofibromatosis	National Neurofibromatosis Foundation	1-800-323-7938
Neuromuscular disease	Muscular Dystrophy Association	1-800-572-1717
Nutrition	National Center for Nutrition & Dietetics Women, Infants, & Children (WIC) Hotline	1-800-366-1655 1-800-WIC-FOR-U
Obsessive-compulsive (see also Mental illness)	Obsessive-Compulsive Foundation OCD Hotline	1-203-878-5669 1-800-NEWS-4-OCD
Osteoporosis	National Osteoporosis Foundation	1-800-223-9994
Ostomy	United Ostomy Association	1-800-826-0826
Ovarian cancer (see also Cancer)	Roswell Park Cancer Institute	1-800-OVARIAN
Overweight	American Heart Association Take Off Pounds Sensibly (TOPS)	1-800-AHA-USA-1 1-800-932-8677
Pain, chronic	American Chronic Pain Association	1-916-632-0922
Parkinson's disease	American Parkinson's Disease Association National Parkinson Foundation Parkinson's Disease Foundation	1-800-223-2732 1-800-327-4545 1-800-457-6676

Poverty	Access to Care Habitat for Humanity International Saint Vincent DePaul Society	1-708-531-0680 1-912-924-6935 1-314-531-2183
Pregnancy, crisis (see also Adoption)	Carenet National Life Center Hotline	1-703-478-5661 1-800-848-5683
Pregnancy, delivery	American Society of Psychoprophylaxis/Lamaze Bradley Method—Childbirth	1-800-368-4404 1-800-422-4784
Pregnancy, postpartum	Depression After Delivery—National Postpartum Support, International	1-800-944-4773 1-805-967-7636
Premenstrual syndrome	PMS Access	1-800-222-4PMS
Prostate cancer (see also Cancer)	American Foundation for Urologic Disease	1-800-242-2383
Psoriasis	National Psoriasis Foundation	1-800-723-9166
Rare diseases	National Organization for Rare Disorders	1-800-999-NORD
Reflex sympathetic dystrophy	RSD Syndrome Association of America	1-609-795-8845
Retinitis pigmentosa (see also vision impairment)	National RP Foundation Fighting Blindness	1-800-683-5555
Reye's syndrome	National Reye's Syndrome Foundation	1-800-233-7393
Rosacea	National Rosacea Society	1-708-382-8971
Runaway child/teen (see also Homeless)	Covenant House Runaway Hotline National Runaway Switchboard Runaway Hotline	1-800-999-9999 1-800-621-4000 1-800-392-3352
Safety	Advocates for Highway & Auto Safety Aquatic Injury Safety Foundation Bicycle Federation of America EPA Safe Drinking Water Hotline DOT Auto Safety Hotline Foundation for Spinal Cord Injury Prevention Mothers Against Drunk Driving (MADD) National Child Safety Council National Coalition to Prevent Childhood Injury National Fire Protection Association National Lead Information Center SafetyBeltSafe U.S.A. USDA Meat & Poultry Hotline	1-202-408-1711 1-800-342-0330 1-202-463-6622 1-800-426-4791 1-800-424-9393 1-800-342-0330 1-214-744-MADD 1-800-327-5107 1-202-884-4993 1-617-770-3000 1-800-LEAD-FYI 1-800-745-SAFE 1-800-535-4555
Scleroderma	United Scleroderma Foundation Scleroderma Federation	1-800-722-HOPE 1-800-422-1113
Scoliosis	National Scoliosis Foundation Scoliosis Association	1-617-926-0397 1-800-800-0669
Senior citizens	American Association of Retired Persons Elder Care Locator Services National Council on Aging Senior Information Services of America	1-800-424-3410 1-800-677-1116 1-202-479-1200 1-800-657-2280
Sexual disease	CDC Sexually Transmitted Disease Hotline Impotence Hotline	1-800-227-8922 1-800-221-5517
Short stature	Short Stature Foundation	1-800-243-9273
Sickle cell anemia	Sickle Cell Disease Association of America	1-800-421-8453
Sjogren's syndrome	National Sjogren's Syndrome Association Sjogren's Syndrome Foundation	1-800-395-6772 1-800-4-SJOGRENS
Skin disease	American Academy of Dermatology	1-708-330-0230
Sleep disorders	American Sleep Apnea Association National Sleep Foundation	1-617-489-4441 1-202-785-2300

Smoking	American Cancer Society American Lung Association	1-800-ACS-2345 1-800-252-LUNG
Speech problem	American Speech-Language-Hearing Association National Aphasia Association Stuttering Foundation of America	1-800-638-8255 1-800-922-4622 1-800-992-9392
Spina bifida	Spina Bifida Association of America	1-301-805-0213
Stroke	American Heart Association National Institute of Neurological Disorders National Stroke Association	1-800-AHA-USA-1 1-800-352-9424 1-800-STROKES
Sudden Infant Death Syndrome	Council of Guilds for Infant Survival National Heart, Lung, Blood Institute SIDS Alliance	1-800-247-4370 1-800-505-CRIB 1-800-221-SIDS
Suicide	American Association of Suicidology American Suicide Foundation	1-202-237-2280 1-212-410-1111
Thyroid disease	American Thyroid Association Thyroid Society	1-800-542-6687 1-800-THYROID
Tinnitus	American Tinnitus Association	1-503-248-9985
Tourette syndrome	Tourette Syndrome Association	1-718-224-2999
Transplanted organ	Bone Marrow Transplant Family Support Network Children's Organ Transplant Association United Network of Organ Sharing (UNOS) Organ Transplant Fund, Inc.	1-800-826-9376 1-800-366-2682 1-800-24-DONOR 1-800-489-3863
Twins/multiple births	National Organization of Mothers of Twins Clubs The Triplet Connection	1-505-275-0955 1-209-474-0885
Urinary incontinence	Help for Incontinent People (HIP)	1-800-BLADDER
Vision impairment	American Council of the Blind Blind Children's Center National Eye Care Project—financial aid for glasses	1-800-424-8666 1-800-222-3567 1-800-222-EYES
Vulvodynia	National Vulvodynia Association	1-941-927-8503