



American Brain Tumor Association

## CAREGIVER RESOURCES

Caregivers face immense challenges as they try to juggle care for their loved one, attend to family responsibilities and in some cases, work outside the home. Whatever your personal situation as a caregiver might be, it is important not to lose sight of ways in which you can care for yourself, in addition to your family member. We hope these resources will be of help to you as a caregiver.

### FACE TO FACE SUPPORT GROUPS

ABTA offers listings of support groups for both patients and caregivers. Please contact ABTA at 800-886-2282 if you would like to receive the list for your state. In addition, many caregiver organizations can help you locate support groups in your area that are specifically for caregivers. Other possible sources for information on caregiver support groups include: your family member's physician, your local hospital or brain tumor treatment center, and/or your local Area Agency on Aging (listed in your phone directory).

### ABTA CONNECTIONS PEN PAL PROGRAM

Connections is a program which helps to connect brain tumor patients or caregivers with others who are in a similar situation. Please call ABTA at 800-886-2282 if you would like to connect with other caregivers. You can also access information for the Connections Pen Pal program at: [www.abta.org/index.cfm?contentid=157](http://www.abta.org/index.cfm?contentid=157)

### ORIENTATION TO CAREGIVING HANDBOOK

The Caregivers Project, a collaboration between UCSF Osher Center for Integrative Medicine and the UCSF Department of Neurological Surgery, offers a *Handbook for Family Caregivers of Patients with Brain Tumors*. This resource helps caregivers understand brain tumors, what to expect, how to care for a loved one, paying for healthcare, planning for the future and much more. It is available for download at:

[www.abta.org/index.cfm?contentid=162&itemtype=2&Caregiving-](http://www.abta.org/index.cfm?contentid=162&itemtype=2&Caregiving-)

Or contact ABTA at 800-886-2282, if you would like a copy mailed to you.

## ONLINE SUPPORT GROUPS AND WEB SITES

There are a variety of internet-based resources, including online support groups, listserves, chat rooms, message boards and other internet communities of interest, through which caregivers can share information and support each other. There are also web sites focused on the needs of caregivers. These internet-based forums offer an alternative for those who do not have access to a face-to-face support group in their area, or who prefer to communicate and seek information via the internet. Access is easy regardless of the weather, time, or location. Most online forums require that you subscribe or register prior to sending messages. After subscribing as directed, you'll receive a confirmation as well as a welcome message. Each forum has its own "netiquette" rules and procedures. Save those guidelines; they will also tell you how to unsubscribe should you so choose. The group may also provide you with directions for obtaining your email in "digest" form—this is a simple way of gathering all the participant messages into one email or one folder. Below are some online support resources and web sites, specifically geared for caregivers.

### AARP

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

A web site for caregivers offering message boards and articles on topics such as guardianship, long distance caregiving and stress management. Caregivers can access extensive tools filled with interactive features, such as expert videos, calculators and worksheets.

### ABTA GROUP ON FACEBOOK

AMERICAN BRAIN TUMOR ASSOCIATION (ABTA)

800-886-2282

<http://www.causes.com/braintumor>

Join the ABTA group to network and socialize with other caregivers of brain tumor survivors and individuals who share the same cause. View photos, videos and upcoming ABTA events.

### AND THOU SHALT HONOR

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

A web site developed in connection with Bill Moyers' PBS Special on caregiving. Includes a caregiving resource center, a directory of community services for caregivers and books and tapes.

### BRAIN TUMOR CAREGIVERS

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

A special interest online community for caregivers of brain tumor patients facilitated through The Healing Exchange Brain Trust.

## CARE TO SHARE CANCER CONNECTION

314-241-1600

[www.nationalchildrenscancersociety.com](http://www.nationalchildrenscancersociety.com)

A moderated online support program of the National Children's Cancer Society for parents to share information and experiences about their children on a wide range of topics. To participate, go to [www.nationalchildrenscancersociety.com](http://www.nationalchildrenscancersociety.com) Click on "Care to Share Message Board" and follow the instructions to register.

## CAREFLASH

[www.careflash.com](http://www.careflash.com)

CareFlash provides a common place on the Internet to share information surrounding a loved one's health circumstances. They also allow the caregiver a way to reach out to their community communicating the needs of the patient. This allows people to donate time, meals or services during a stressful time. This is all available in a private, organized website, individual for each patient. Also available are hundreds of 3-D healthcare animations on a variety of health related topics. These are available in Spanish, Arabic, Dutch and Hungarian.

## CAREGIVER MEDIA GROUP

800-829-2734

954-893-0550

[www.caregiver.com](http://www.caregiver.com)

A web site offering internet discussions, a care directory, listings of caregiver support groups throughout the country, carelinks, caregiver stories, and a Caregiver Mall, which offers books videos, products and services for caregivers. This organization also hosts an annual caregivers conference and publishes print and online versions of "Today's Caregiver" magazine, which features guest columns, Caretips, and CareNotes. Hosts conferences throughout the United States

## CAREGIVERS DIRECTORY

[www.caregiversdirectory.com](http://www.caregiversdirectory.com)

Offers articles on caregiving, information about support groups, a Caregiver's Resource newsletter and links to a variety of services for caregivers, including products, adult day care, home health, homemaker, hospice, nursing home and respite services by state. It is designed to view caregiving as a progressive continuum through the planning, decision making and hands on stages of illness.

## CAREPAGES

888-852-5521

[www.carepages.com](http://www.carepages.com)

CarePages is a service that allows caregivers to create their own webpage to share information with designated family and friends. Sponsored by several healthcare organizations and hospitals, this service is free to families.

## CARINGBRIDGE

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

This web site gives caregivers the ability to create a personal webpage to share information with designated family and friends. It eases the burden of keeping family and friends informed. Patients and caregivers can draw strength from messages of support.

## CARINGROAD

651-452-7940

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

An interactive online caregiver support network. Also offers practical information and personal stories. CaringRoad was created to connect family caregivers seeking the support and friendship of other family caregivers in an online community.

## CENTER FOR FAMILY CAREGIVERS

773-343-6341

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

Offers a variety of resources for caregivers, including online support groups, an e-newsletter, caregiver message board, a caregiving packet, caregiver stories, tips, seminars and workshops.

## FAMILY CAREGIVER ALLIANCE

National Center on Caregiving  
800-445-8106

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

An online discussion groups for caregivers. Also offers literature and resource information, including a newsletter, fact sheets in English, Chinese and Spanish, information about specific diseases and caregiving advice and strategies.

## LOTS A HELPING HANDS

[www.lotsahelpinghands.com](http://www.lotsahelpinghands.com)

A free web service that allows caregivers to coordinate caregiving needs among friends and family members and other helpers. It's an easy to use, private group calendar, specifically designed for organizing helpers, where everyone can pitch in to help with tasks necessary for life to run smoothly during times of medical crisis or family caregiver exhaustion. It also offers a place to keep friends and family informed with updates, photos, message boards and more.

## MYLIFELINE.ORG

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

Offers a helping calendar, an easy tool where friends and family can view the treatment schedule and learn how to best help. Also provides learning links, joke of the day and inspirational messages.

## NATIONAL ALLIANCE FOR CAREGIVING

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

Offers links to caregiver organizations and resources for caregivers and professionals. Their goal is to improve the quality of life for families and care recipients.

## NATIONAL ORGANIZATION FOR EMPOWERING CAREGIVERS

[www.care-givers.com](http://www.care-givers.com)

Offers a variety of online forums for caregivers, articles on caregiving, a print and online newsletter, caregiver stories, featured expert columns and emotional and spiritual support through journaling, healing circle, inspiration and humor.

## NATIONAL RESPITE LOCATOR SERVICE

919-490-5577

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

Respite services offer a temporary break from caregiving responsibilities for caregivers of those with disabilities, chronic and life threatening illnesses. Call or search web site for services in your state.

## NET OF CARE

Department of Pain Medicine and Palliative Care

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

Net of Care is a resource network for caregivers. Their site helps caregivers feel less isolated and overwhelmed by making them be the best caregiver they can be. Their site features online support, education and information on the daily aspects of caregiving. As well as searchable local and national resource database, telephone support groups and an E-newsletter.

## WELL SPOUSE ASSOCIATION

800-838-0879

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

Offers bulletin boards, an email listserv and an online mentorship program to link a spouse caregiver to another more experienced spouse caregiver by email or phone. Also offers “round robins” to connect spouses to each other through letter writing and face-to-face support groups throughout the country. Provides literature and a quarterly newsletter, “Mainstay” for members.

## WHAT FRIENDS DO

[www.whatfriendsdo.com](http://www.whatfriendsdo.com)

What Friends Do is designed to coordinate the support of friends and family for individuals experiencing a crisis or life changing event. Helping a friend through a life-changing event involves lending a hand with meals, transportation and other tasks. The site offers its users the ability to create a free custom website to support a friend during a life-changing event.

## RESOURCES FOR STRESS MANAGEMENT AND SELF-CARE

Many hospitals now offer programs that utilize the connection between mind, body and spirit to promote relaxation, anxiety management and wellness. You can contact the social work department or center for integrative medicine at your local hospital or medical center or your doctor’s office to see what programs or classes are available in your community.

## CARE TRUST PUBLICATIONS

800-565-1533

[www.comfortofhome.com](http://www.comfortofhome.com)

Offers a variety of resources for caregivers including a CD and audio tape for stress reduction and meditation designed for caregivers, books, videos and caregiver links.

## HEALTHJOURNEYS

800-800-8661

[www.healthjourneys.com](http://www.healthjourneys.com)

Offers a variety of videos, cassettes, CDs, software and books to promote relaxation, wellness and healing. Products include resources on guided imagery, meditation and self-care.

## SOOTHING THE SENSES CD

888-357-5867

[www.sensoryresources.com](http://www.sensoryresources.com)

A musical CD of gentle piano pieces performed by jazz pianist Fred Hersch to help their mind, body and spirit relax. Available from Sensory Resources.

## ORGANIZATIONS AND PROGRAMS

### CANCERCARE

800-813-4673

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

Offers a telephone support group and an online support group for caregivers. Also offers a variety of resources, including telephone education workshops, caregiver links, a bookstore on caregiver issues, practical tips and suggestions for coping with the emotional issues affecting caregivers. These services as well as counseling, financial assistance and practical help are provided by trained oncology social workers free of charge.

### FAITH IN ACTION

877-324-8411

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

A nationwide interfaith volunteer caregiving program of The Robert Wood Johnson Foundation, offering services to individuals with long term disabilities and their families. Services include providing rides, running errands, home visiting and helping with day-to-day tasks such as bill paying. Can search web site by state or zip code for Faith In Action programs throughout the country.

### AMERICAN RED CROSS FAMILY CAREGIVING PROGRAM

[www.redcross.org/services/hss/care/family.html](http://www.redcross.org/services/hss/care/family.html)

A program to teach skills to family caregivers. Offers hour-long modules on topics such as home safety, personal care, care for the caregiver, and legal and financial issues. To find a program near you, contact your local American Red Cross Chapter, listed in your phone directory or search online.

THE NATIONAL COALITION FOR CANCER  
SURVIVORSHIP (NCCS)  
877-622-7937

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

Offers information about caregiving through online resource, “Essential Care” accessible from their web site. Also offers the Cancer Survival Toolbox Educational Program on a range of topics, including “Care for the Caregiver.” Available to listen online or as a CD.

NATIONAL FAMILY CAREGIVERS ASSOCIATION  
800-896-3650

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

Offers practical information, support and public awareness resources and a variety of publications.

STRENGTH FOR CARING PROGRAM  
866-466-3458

[www.strengthforcaring.com](http://www.strengthforcaring.com)

Offer caregiving tips, practical advice for daily care, information on money management, health insurance, legal issues and living options. Message board available.

THE WELLNESS COMMUNITY  
888-793-9355

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

Provides free psychological and emotional support to cancer patients and their families. Facilitates support groups, offers help with stress reduction, cancer education, workshops, classes and social events. Call or visit their web site to obtain a list of their centers throughout the US. Also offers a virtual wellness community through which services can be accessed online.

GOVERNMENTAL RESOURCES

CENTERS FOR MEDICARE SERVICES  
800-633-4227

[www.medicare.gov](http://www.medicare.gov)

Offers a publication, “Medicare Basics: A Guide for Family and Friends of People with Medicare” that addresses Medicare coverage for home health, prescription drugs and nursing home care. Downloadable from their website or available to order free of charge.

## FAMILY MEDICAL LEAVE ACT

866-487-9243

[www.dol.gov/esa/whd/fmla/](http://www.dol.gov/esa/whd/fmla/)

Legislation that requires employers with 50 or more employees to offer up to 12-weeks of unpaid leave to eligible employees to care for a seriously ill family member (spouse, child or parent). For more information about this Act contact the US Dept. of Labor, Employee Standards Administration, Wage and Hour Division.

## NATIONAL FAMILY CAREGIVER SUPPORT PROGRAM

202-619-0724

[www.aoa.gov](http://www.aoa.gov)

A program developed by the Administration on Aging of the US Dept. of Health and Human Services (HHS) following enactment of the Older Americans Act Amendments of 2000. It provides services for caregivers in partnership with Area Agencies on Aging and local community service providers, including information, assistance in accessing support services, caregiver training and respite care. At their web site click "Elders and Family" then click "For Caregivers." You can also call your local Area Agency on Aging in the city or government section of the telephone directory or look under "Aging" or "Social Services."

## PRODUCTS FOR HOMECARE

### THE CAREGIVERS MARKETPLACE

[www.caregiversmarketplace.com](http://www.caregiversmarketplace.com)

An online store for caregiver products. Offers a cash back program for eligible products, such as nutrition, incontinence, bathing, skin care, digestive health and more.

You can look in your local phone book or on the internet under "medical supplies." You can also contact the caregiver organizations in this listing for help in locating suppliers of home care products.

## BOOKS

***American Medical Association Guide to Home Caregiving.*** Angela Perry, Editor. American Medical Association. Written by experts from the AMA, this comprehensive resource provides information on developing a care plan for your loved one, basic and specialized caregiving skills, choosing a home health provider, paying for home health care, rehabilitation services, nursing homes and end of life issues. Also addresses "care for the caregiver" issues. John Wiley & Sons, Inc., Hoboken, New Jersey. 2001.

***A Caregivers Story: Coping with a Loved One's Life Threatening Illness.*** Ann Brandt. The author shares her story about caring for her husband after he was diagnosed with a brain tumor. She offers spiritual as well as practical advice on how to make caregiving more manageable. She includes information on how to get a second opinion, find support groups, locate emotional and financial support services and connects prayer and healing. iUniverse, Lincoln, NE. 2007.

***Caregiving: A Step-By- Step Resource for Caring for the Person with Cancer at Home, Revised Edition.*** Peter S. Houts, PhD, Julia A. Bucher, RN, PhD. A practical guide offering guidance on the issues and situations that caregivers deal with on a day-to-day basis. Offers information on cancer treatments and their side effects and advice on facing the practical as well as the emotional challenges of caregiving. Provides a resource guide and information on how to obtain help from community agencies and volunteer groups. Can be ordered directly from the American Cancer Society at 800-227-2345. American Cancer Society, Atlanta, GA. 2000.

***Caregiving: The Spiritual Journey of Love, Loss, and Renewal.*** Beth Witrogen McLeod. A personal reflection on the joys and trials of caregiving. The author interweaves her story with the stories of other caregivers, drawing on the wisdom of many faith traditions. Emphasizes the emotional, spiritual and psychological aspects of caregiving. Contains support strategies and a useful guide for resources. John Wiley & Sons, Inc., Hoboken, NJ. 2000.

***The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers, 2<sup>nd</sup> Edition.*** Maria M. Meyer, Paula Derr, RN. Offers suggestions to help families decide what level of home care is needed or possible, along with practical tips on managing personal care and everyday activities, avoiding infections and illnesses, and making your home safe for the ill family member. Provides information on supportive housing and other care options. CareTrust Publications, LLC, Portland, OR. 2002 . Available in English and Spanish.

***The Comfort of Home Caregiving Journal.*** Maria M. Meyer, Paula Derr, RN. Companion book to *The Comfort of Home: An Illustrated Step-by-Step Guide for Caregivers*. A spiral bound book that allows caregivers to write in physician care plan instructions, medication schedules and medical history. Also offers lined spaces for daily journal entries in which caregivers can write their thoughts and feelings, care reminders and notes for each day, weekly reminders, inspirational quotes and home safety checklists. CareTrust Publications, LLC, Portland, OR. 2003.

***The Complete Bedside Companion: A No-Nonsense Guide to Caring for the Seriously Ill.*** Rodger McFarlane and Philip Bashe. A comprehensive resource offering practical wisdom and hands-on guidance on all aspects of caring. Topics include working with the hospital and medical team; dealing with financial and insurance issues, managing the emotional aspects of caregiving, the basics of daily caregiving, finding support, care for the caregiver and end of life issues. Offers step-by-step instructions on bathing, wound and skin care, toileting, lifting, grooming, dressing, managing pain and administering medications. Sections on specific medical conditions such as cancer, stroke, brain injury and neurological disorders. Simon & Schuster, New York, NY. 1999.

***Daily Comforts for Caregivers.*** Pat Samples. Written for caregivers, this book offers daily meditations on topics related to caregiving. Each meditation ends with a helpful affirmation. Also includes a helpful topic index. Fairview Press, Minneapolis, MN. 1999.

***Family Caregiver Guide: A Comprehensive Handbook for Caring for Your Loved One at Home.*** Shelly Schonhoff, RN-C and Joanna Speaker, RN-C. Written by nurses this book provides information on home safety, personal hygiene, eating and nutrition, incontinence problems, mobility, caregiving skills and comfort measures, communication, sleep disturbances, and the emotional, psychological and spiritual aspects of caregiving. First aid, handling emergencies, legal, ethical and financial issues are covered as well. Simon & Kolz Publishing, Dubuque, IA. 1998.

***Family Caregiver Speaks Up: "It Doesn't Have to be This Hard"***. Suzanne Mintz. A practical guide that focuses on the day-to-day needs and wellbeing for the caregiver. Written by the president and co-founder of the National Family Caregivers Association. To order call 703-661-1571 or [www.nfcacares.org](http://www.nfcacares.org) Capital Books, Inc., Sterling, VA. 2008. *BN.com*.

***The Fearless Caregiver: How to Get the Best Care for Your Loved One and Still Have a Life of Your Own.*** Gary Barg, Ed. A practical guide to caregiving edited by the publisher and editor of "Today's Caregiver" magazine. Addresses topics such as communicating with physicians, respite, long term care options, developing a care plan, disability and rehabilitation terminology, wills and power of attorney issues and making the home safe. Also contains inspiring personal stories, help with caregiver emotions and caring for self. Capital Books, Inc., Sterling, VA. 2003.

***Home Care for Seriously Ill Children: A Manual for Parents.*** Edited by Stacy Orloff, LCSW, EdD and Susan M. Huff, RN, MSN (Eds.). Offers concrete advice on topics ranging from medications and pain control, controlling medical problems, attending to general care, such as nutrition, mouth, skin and eye care, daily activities, medical equipment and supplies, emotional concerns, finding support and end of life issues. Children's Hospice International, Alexandria, VA. 2003.

***The Magic of Humor in Caregiving.*** James R. Sherman, PhD. Explores the healing benefits of laughter to aid in coping with the stresses of caregiving. Pathway Books, Gilsum, NH. 1995.

***Quick Tips for Caregivers.*** Marion Karpinski, RN. Provides instructions for basic caregiving, including caregiving procedures, medications, wheelchair use, nutrition and infection control. Also covers stress reduction and obtaining outside support. Available in English and Spanish. Healing Arts Communication, Milford, OR. 2000.

***Share the Care: How to Organize a Group to Care for Someone Who Is Seriously Ill, Revised and Updated Edition.*** Cappy Capossela and Sheila Warnock. Offers step-by-step instruction on how to form a “share the care” group, a support system that brings in friends and family members to perform tasks, run errands and provide support and companionship for the one who is ill. Simon & Schuster, New York, NY. 2004.

***When Life Becomes Precious: A Guide for Loved Ones and Friends of Cancer Patients.*** Elise Needell Babcock. A helpful handbook that provides step-by-step guidelines for friends and family members to help them be supportive to the patient. Covers topics such as avoiding caregiver burnout, managing fear and anger, how to handle holidays, as well as explaining the disease to children. Bantam Books, New York, NY. 1997.

This information is not intended as a substitute for professional medical advice and does not provide advice on treatments or conditions for individual patients. All health and treatment decisions must be made in consultation with your physician (s), utilizing your specific medical information. The American Brain Tumor Association does not endorse any of the organizations listed or guarantee that individuals will qualify for the services they provide. Please contact each organization for their specific guidelines.

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