

caregiver's corner



Participants gather in San Antonio for the National Family Caregiver Training Program.

caregivers gathered in Boston, Los Angeles, Minneapolis, Virginia, and San Antonio to learn practical skills and information from health professionals. Sessions included presentations from neuro-oncologists about brain anatomy, tumor types, and treatment options; sessions with a nurse about managing symptoms at home and recognizing and coping with emergencies; a presentation by a neuropsychologist about how brain tumors affect the personality and cognitive function and how families can better cope with these changes; an interactive session with physical and occupational therapists about how to safely assist people with mobility problems to avoid injury; a discussion with a lawyer about legal issues for caregivers and an overview of important paperwork to have on hand; an overview of community resources by a social worker; and a discussion about quality of life, end of life, and hospice.

Mothers, fathers, sons, daughters, cousins, friends, and parents all gathered together, joined by their love for someone with a brain tumor. Over lunch, participants had a chance to talk with one another and find support. Throughout the day, caregivers asked and answered questions for each other. At the end of the day, participants returned home with a detailed resource manual and a better understanding of brain tumors and how to cope and better support their loved ones.



Each participant receives this 150-page manual.

Of those who participated in this training, over 85% of caregivers gained knowledge about how to cope with cognitive and personality changes in their loved one, 70% gained knowledge about useful local resources and important legal affairs, and 70% gained specific medical or symptom knowledge that was new and helpful in caring for their loved one. According to one participant, "I wish I had known this information all along. It filled in all the gaps that the hospital did not. I feel so much more prepared now."

This program was made possible with a gift from the Argosy Foundation.

Helping Brain Tumor Patients by Helping Caregivers

The National Brain Tumor Foundation launched a national training program for family caregivers last fall, the first of its kind developed specifically for brain tumors. It is designed to offer, in one day, an overview of the essential information that family caregivers may need to know at some point during their loved one's diagnosis, treatment, and survivorship.

Over the past year,

Free Caregiver Workshop

Ft. Lauderdale, FL
June 4, 2005

Sign up Now! Call
800.934.2873 or email
patterson@braintumor.org

Resource Box

Need to Hire In-Home Help?

What types of help are available?

Home care workers help with household duties and personal care such as bathing, dressing, and toileting. You can hire an individual, hire using an agency, or enlist volunteer help through a religious or community group you belong to. You may also qualify for home care through your health plan, long term care insurance, or hospice. *Home healthcare workers* can assist with medical needs such as operating medical equipment, giving injections or medication, or in-home physical or speech therapy. Home healthcare must generally be prescribed by your physician.

How do I find someone reputable?

Consider asking family and friends for recommendations for agencies or individuals. Homecare online, a service of the National Association for Home Care and Hospice, offers a home care locator database on their website. Visit their website, www.nahc.org/Consumer/coninfo.html for information about home care and to find a reputable provider near you to meet your needs. Local Agencies on Aging may also have a list of providers in your state or county. The social services department of your hospital will have referral agencies as well.

What do I need to be aware of when hiring help?

Hiring an individual is generally cheaper than going through an agency. However, you will also be responsible for employment-related taxes and may need to check your home liability policy about coverage for workers in your home. Also, consider the specific care needs of your loved one. Home healthcare workers include RNs, LPNs, and LVNs, and there are different pricing schedules depending on the worker's qualifications.

Checking references is important no matter which approach you take. For a detailed list of questions to ask when interviewing home help agencies or individuals, visit our website at: www.braintumor.org and click on "What's New" or call 800.934.2873.