Care Options

Families living with a brain tumor may experience physical and emotional fatigue. However, there are various care options for you to consider, which can help alleviate stress and provide quality long-term care. These options include home care, adult day care, assisted living facilities and nursing homes. In addition to these options, ask a social worker to help you locate community-based resources and programs.

Adult Day Care Services
Adult Day Care Services are community-based, supportive programs designed to meet the needs of adults who are having difficulties performing daily living activities. Those experiencing difficulty processing thoughts, recognizing familiar surroundings or having memory problems may also be eligible for these programs.

In choosing an adult day care, think about your family members’ needs as well as your own. Consider the available physical and occupational therapies, socialization opportunities, healthcare monitoring and personal care services from which your family member may benefit. Programs offering these services provide the caregiver with occasional free time, coverage while working, and emotional support. These services can alleviate stress and improve time management for both you and your family. Listed below are some resources that may help families locate appropriate adult day care services.

Easter Seals helps family members locate adult day care services in their area. They offer assistance to those individuals with a physical disability and/or to individuals who may be disoriented with their surroundings. You can contact Easter Seals at 800-221-6827 or www.easterseals.com. They will help you locate programs in your area.

NADSA - The National Adult Day Services Association provides national resources for adult day care services. Some of the resources found through NADSA include transportation, nursing care, personal care, rehabilitation therapies, meals and counseling. Contact NADSA’s office at 800-558-5301 or at www.nadsa.org

Care in the Home
“Home care” includes a variety of health and social services. Generally, home care is chosen when your family member needs constant care and your family cannot solely provide that care.

Home care services are available 24 hours a day, seven days a week. Nurses, therapists, social workers and volunteer homemakers can all be arranged. Some families are comfortable with one professional caregiver who lives with them. However, others may need a team that can provide a range of services.
Choosing a home care service may seem like an overwhelming and difficult task. Begin by creating a checklist of questions that can assist in selecting an appropriate service. Some important questions to consider are:

- How long has the provider been serving the community?
- What literature is available on the services?
- What type of evaluation is done regarding the type of home care the patient will receive and who completes the evaluations?
- Do they provide the family with treatment and progress updates?
- How does the agency handle problems and emergencies?

The National Association for Home Care and Hospice can provide information on Home Health Agencies, Hospices, Homemaker and Home Care Aide Agencies. They can be contacted at 202-547-7424 or on the web at www.nahc.org. The Visiting Nurse Associations of America can provide referrals for nursing care in the home by calling 202-384-1420 or www.vnnaa.org.

Respite care is another option for caregivers and families. Respite care provides temporary relief for families and caregivers who are caring for a patient with a chronic and serious illness, thereby reducing stress. Respite care can occur in the home or in a variety of out-of-home settings. This is a service that temporarily provides at-home care, but is not a substitute for home care services. The National Respite Locator helps caregivers find respite services in their area and help to determine if they qualify for this service. They can be contacted at 919-490-5577 or www.respitelocator.org.

Faith in Action provides volunteers to help care for those who are disabled or face long-term health conditions. The volunteers may assist by providing a ride to the doctor, running errands or just providing company. To locate a Faith in Action program near you, contact them at 877-575-4932 or you may search their database at www.fianationalnetwork.org.

National Private Duty Association, www.privatedutyhomecare.org is the nation’s first association for providers of private duty home care. NPDA members provide both home health care and non-medical home care services such as companion care, elder care and in-home assisted living services. You can search their website for providers in your area or call 317-663-3637.

Assisted Living Facilities
Assisted living facilities are primarily for individuals seeking assistance with activities of daily living yet the programs promote to enhance independence as much as possible. They can be seen as a cross between an apartment and a nursing home, and may include meals, housekeeping services, transportation and activities- all for a monthly fee. Interview various facilities thoroughly as they vary tremendously and looks can be deceiving. Providing a beautiful homelike appearance should not be a trade off for a safe and secure environment. Also, make sure to see if they cater to the needs of all residents rather than just those over the age of 65.

Visit a few facilities with an appointment and also show up unexpectedly and ask to view the facility. A checklist is a helpful tool in finding the appropriate center. Some questions to include on your checklist may include the following:

- How will the facility accommodate your family member’s current and future needs?
- Where are the closest hospitals and other supportive services?
- Does your physician make rounds at the facility?
• What is the schedule of activities for patients and family members?
• What type of contract is required?
• What types of conditions are accepted? Does it include servicing clients who have memory loss, impaired thinking abilities, or limited mobility?
• Is the staff licensed health care and/or rehabilitation professionals?

Interview the staff and observe their services, what does the facility feel like to you? If your family is not satisfied with the services residents are receiving, it is important to discuss this with the staff. Set up a staff meeting to discuss how they can make this transition easier for everyone.

The Assisted Living Federation of America represents over 7,000 providers of assisted living services. They are dedicated to advancing the assisted living industry and enhancing the quality of life of the residents it serves. You can contact them at 703-894-1805 or www.alfa.org to locate an assisted living facility in your area.

Contact the Consumer Consortium on Assisted Living (CCAL), a national, nonprofit consumer advocacy organization for more helpful tips and tools at www.ccal.org or 732-212-9036.

Nursing Home Facilities
Nursing homes are an option when a family member has physical and/or mental impairments, which can prevent them from living independently. Nursing homes must be certified to provide different levels of care such as basic care, sub-acute care and skilled nursing care. The best nursing homes offer a full array of nursing and personal assistance, dietary, therapeutic, social and recreational services. Meals, laundry, housekeeping and medical services should also be provided. Nursing homes can be for profit as well as non-profit community or religious affiliated programs.

As with an assisted living facility, visiting the nursing home as well as asking similar questions on the checklist above is very important in choosing the right facility. As much as possible, involve your family member in the decision of choosing the facility. You can access “Nursing Home Compare” at www.medicare.gov. It will provide you with detailed information about the performance of every Medicare and Medicaid certified nursing home in the United States.

Financial Obligations and Coverage
Once you narrow your list of care options, you will want to discuss fees and payment options. Begin by checking your insurance coverage for details on home health care, assisted living and nursing home coverage. Some policies have a specific amount of hours or visits they will pay for while others have a lifetime limit.

If you do not have insurance coverage, some facilities have sliding scale fees. These fees are usually based upon your family income.

If an individual is homebound, under a physician’s care and requires a skilled nursing facility or therapy services, he or she may be eligible for services under the Medicare program. In order to be eligible for Medicare coverage, the patient has to meet specific coverage criteria.

Some agencies also receive special funding from state and local governments and community organizations to cover the costs of needed care through their social services and medical assistance programs.
Medicare certified facilities have to meet federal requirements for patient care and management. If the patient has Part A Medicare, skilled care coverage is limited to licensed professionals providing such care. These professionals include, for example, nurses, therapists or physicians. Medicare will not usually cover “custodial care” such as assistance with daily living activities. Part B Medicare may include services such as skilled nursing care if eligibility requirements are met (this may possibly include no deductible) and they may also pay approximately 20% of medical equipment costs.

Medicare plans vary according to the state you live in. They may also have contracts with certain nursing facilities, and most will require a treatment or care plan form your physician. Specific questions on what Medicare/ Medicaid will cover can be directed to your state office or contact the Centers for Medicare and Medicaid Services at 800-633-4227 or www.cms.hhs.gov.

Additional Resources

Carers UK
020-7378-4999
www.carersuk.org
A support network in the UK for people caring for family members with illness or disability.

Eldercare Locator
800-677-1116
www.eldercare.gov
Provide comprehensive referral services for the elderly.

Long Term Care Living
202-842-4444
www.LongTermCareLiving.com
An online guide to planning, preparing and paying for long term care for yourself or for a loved one. Brochures such as Planning Ahead, Having the Conversation about Long Term Care, and guide to Nursing Homes can be downloaded at their website or ordered free of charge.

National Clearinghouse for Long-Term Care Information
800-896-3650
www.longtermcare.gov
Provides information and resources to help families plan for long-term care needs. Website offers information on understanding, planning and paying for long-term care.

National Family Caregivers Association
800-896-3650
www.nfcacares.org
Provides education, support, respite care and advocacy for caregivers.

OurParents
800-321-0294
www.ourparents.com
OurParents is a free and unbiased service focused on helping families with aging parents find the best senior care solution that meets their loved one’s unique needs, be it an in-home caregiver, an assisted living facility, or a nursing home.

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.