Respite

Respite is a service that provides family caregivers with time away from their caregiving responsibilities. Everyone needs “me” time to relax and reboot—this is especially true for family caregivers, who are often stretched thin emotionally as well as physically by the increased demands illness places on the family. Respite gives the caregiver a chance to meet his or her own needs, which benefits both the caregiver and the care recipient.

Respite arrangements

There are many different types of respite arrangements. Respite can be provided in the home, or outside of the home. It can be provided through a formal program, or through an informal support network made up of other family members, friends, and volunteers from the community. Respite may be scheduled at regular intervals, or on an as-needed or emergency basis. The length of the respite period can also vary, from a few hours to a few days. Many families who are coping with an ongoing, debilitating illness rely on a variety of respite arrangements to meet their needs.

Home health agencies and non-medical home care (companion) agencies offer in-home respite services, or you can consider hiring a respite caregiver on your own. Adult day service programs are a source of respite outside of the home, although these often tend to be geared toward older adults, so care must be taken to ensure that the program is age-appropriate. When respite services are needed for a longer period of time (e.g., overnight or for a few days) or when the care recipient requires a great deal of assistance or skilled care, a short-term stay program through a local hospital, long-term care facility, or assisted living facility may be the best option.

Your local ALS Association chapter may offer respite services, or be able to provide information about respite care resources available in your area. If you have a local ALS Association chapter, please contact them for more information.
Paying for respite services

Funding to help pay for respite services can come from a variety of sources. Your state’s lifespan respite program or respite coalition (see the Respite Resources sidebar) may be able to help you identify sources of funding, including those that are unique to your state.

Medicare

Medicare covers respite care as part of its hospice benefit. To qualify for the hospice benefit, the beneficiary must have Medicare Part A, the doctor must certify that the beneficiary has 6 months or less to live, and the beneficiary must sign a statement agreeing to accept only palliative care (i.e., care directed at preventing and relieving suffering, not prolonging life). Beneficiaries who qualify for the Medicare hospice benefit are eligible to receive respite care in a Medicare-certified hospital or skilled nursing facility for up to 5 days at a time. There is a co-pay of 5%; Medicare will pay the remaining 95% of the Medicare-approved amount for in-patient respite care. Additional respite benefits may be provided as part of a Medicare Advantage Plan (Medicare Part C).

Medicaid

Respite services are frequently covered under Medicaid 1915 (c) Home & Community-Based Waiver programs. Medicaid personal care benefits can also be used to provide periods of respite.

Respite Resources

The following organizations and programs can provide additional information about respite services and assist with locating appropriate respite programs in your area.

- The Access to Respite Care and Help (ARCH) National Respite Network and Resource Center works to assist and promote the development of quality respite and crisis care programs in the United States. The organization maintains a respite locator tool on its website.
- State Respite Coalitions are grassroots membership organizations. Members often include for-profit, non-profit and governmental organizations that serve people of all ages with disabilities and chronic conditions, as well as family caregivers. The primary focus of the state respite coalition is usually on raising public awareness and advocating for family caregivers, but some state respite coalitions also provide training for respite providers, financial assistance in the form of voucher programs, or both.
- State Lifespan Respite Programs are run by a designated state government agency that works collaboratively with the state respite coalition and the state Aging and Disability Resource Center. The state lifespan respite program is responsible for implementing coordinated, community-based respite services at the local and state level.
- State Aging and Disability Resource Centers assist families with accessing long-term support services for older adults and people with disabilities of all ages.
- Centers for Independent Living are community-based organizations that provide information and a variety of services to people with disabilities.
Veterans Health Administration
The VA health program includes many benefits designed to support family caregivers, including a respite care benefit and the homemaker and home health aide program. In-home respite services, as well as short-term respite stays in VA community living centers, VA-contracted community residential care facilities, and adult day health care centers are covered, and the benefit provides up to 30 days of respite care annually. The homemaker and home health aide program can also be used to provide periods of respite.

Voucher programs
State offices, faith-based organizations, and charitable organizations may sponsor voucher programs to offset the costs of respite services. These programs are administered in a variety of ways. Usually, it is necessary to submit an application and the application must be renewed at regular intervals. The program may require families to choose respite services from a list of approved providers, or the choice may be open-ended. In some cases, the family pays the respite provider and is reimbursed by the program, and in other cases, the voucher program pays the provider directly. The ALS respite care voucher program is sponsored and administered by local ALS chapters.

Bibliography
