

Resources for Seniors With Limb Differences and Their Caregivers

by Rick Bowers

Your mother is 97. She's a bilateral leg amputee, her diabetes is out of control, and she's fighting colon cancer to stay alive. Sometimes, she is so heavily medicated that she doesn't even know where she is or who she is. You have struggled for months to care for her at home, and it's taking an emotional and physical toll on you. Even worse, you realize that your mother is not getting the care she needs and that it is endangering her health.

What do you do? More than likely, you'll put her in some type of facility like a nursing home where you hope she will get the care she needs. You'll then feel guilty that you didn't do more, but, in this case, it was probably the right decision. However, in many cases, it is not.



Connie Siskowski

Siskowski, RN, MPA. Unfortunately, older individuals often find it difficult to perform many of the daily tasks they must do to live a normal life. And these difficulties may be even greater if they are missing an arm, a leg or several limbs. In fact, many older amputees might also have one or more secondary physical conditions, such as diabetes or peripheral vascular disease, back problems, bone density and muscle loss, problems caused by the overuse of one limb, osteoporosis, skin problems, added stress on the heart, or added risk of cardiovascular problems due to inactivity. Additionally,

“No matter how old they get, most people would prefer to continue living in their own home rather than in an institution,” says caregiving consultant Connie

there are often mental health concerns.

It might be a terrible error, however, to put them in a nursing home or assisted-living environment when all they might need is just a little help – something as basic as having someone check in on them, prepare their meals, give them their medication, tidy their home or deliver their groceries.

Historically, much of this type of caregiving assistance has been done by family members. Unfortunately, in the modern world, not everyone has family members who live nearby or who have the time to devote to taking care of them every day. In addition, Medicare cuts and managed care limits for home care and home healthcare services may make the situation seem even bleaker.

“Fortunately, there are more resources and assistance available for family caregivers than ever before,” says Siskowski, who attributes the increase largely to the federal government's National Family Caregiver Support Program, which has allocated dollars to each state. There are numerous agencies, organizations and products available to help these individuals, she points

out, and, in some cases, financial assistance might even be available.

“Because facility care is more expensive,” Siskowski explains, “some states have been trying models where they provide financial support for people to stay at home with home care.” In some places, they give monthly stipends or vouchers to family members. In different forms of consumer-directed care, which have been implemented in some states, families are given money, and they can choose which types of care to purchase with those dollars from a menu of covered services. In addition, there are other programs like Boca Raton Interfaith in Action, which Siskowski founded, that offer volunteer respite providers to give family caregivers a break. There are also some caregiver relief programs where workers receive less than minimum wage to provide respite care, as well as some programs where respite is provided in adult day-care or medical day-care facilities. These facilities, some of which have extended evening hours and transportation services, are especially useful for caregivers



who are employed because they allow the caregiver to go to work while their loved one is being taken care of and perhaps getting the opportunity to socialize.

Because of all the possibilities for assistance, before considering an expensive nursing home or even expensive in-home medical care, the extent of the individual's difficulties should be determined. Often less expensive companion care, automated assistance, and housing modifications can solve the problem. Such solutions might include a personal help button that can be used to summon emergency assistance, adding safety bars in the bathroom, moving the individual to a one-level home, volunteer companions, inexpensive housekeeping services, canine companions, a computerized medication reminder system, and lifts that help people out of beds and chairs. In addition, such high-tech devices as the Nursebot, a personal robotic assistant for the elderly, are being tested and may be available within the next decade to help people in their homes.

The following is a list of resources that might help seniors with disabilities and their caregivers start searching for the many types of assistance that are available.

NOTE: Inclusion in this list does not connote endorsement of any products or services by the Amputee Coalition of America, the National Limb Loss Information Center, or the Centers for Disease Control and Prevention.

Area Agencies on Aging (AAA)

These agencies provide information about groups that provide home-delivered meals, transportation, home health services, employment services, adult day care, and other services. **Telephone:** Check in the local telephone directory's Yellow Pages under "Senior Citizens Services and Organizations." **Web site:** www.aoa.dhhs.gov/agingsites/state.html

Assistive Technology Act Projects

These projects, which exist in every state, commonwealth and territory of the United States, work to reduce or eliminate barriers that impede access to and funding for assistive technology devices and services for individuals with disabilities of all ages. **Telephone:** 703/524-6686 (ask to speak to a Technical Assistance Project staff member)

Web site: www.resna.org/taproject/at/statecontacts.html

Beep 'N Tell Medication Reminder from E-Pill

This special pill bottle has an alarm that beeps loudly when it's time for patients to take their medication. Also allows patients or caregivers to record reminders.

Web site: www.epill.com

"Benefits Check Up"

This free and simple online service allows seniors to search more than 1,000 federal and state programs and find those they might be eligible for. **Web site:**

www.benefitscheckup.org

Canine Companions for Independence (CCI)

Nonprofit organization that provides free assistance dogs for eligible people with disabilities. There is a \$100 Team Training registration fee, which is reimbursed in supplies. **Telephone:** 800/572-2275, **Web site:** www.caninecompanions.org

Caregiver Background Screening Service

Offers tips for hiring assistants for seniors.

Web site: www.dmh.missouri.gov/hr/careback/caregive.htm

Caregiver.com Weekly Newsletter

Free newsletter. **Web site:** www.caregiver.com

The Caregivers Marketplace

This is a group-purchasing plan that offers savings to family caregivers on a variety of selected products and services that they are likely to purchase regularly.

Telephone: 866/327-8340, **Web site:** www.caregiversmarketplace.com

Children of Aging Parents (CAPS)

A caregiver's organization that offers information, education, support groups and referrals to children who are taking care of their parents. **Telephone:** 800/227-7294, **Web site:** www.caps4caregivers.org

Department of Social Services

Every state and many local governments have a Department of Social Services (sometimes called Department of Health & Social Services or Department of Health & Human Services). The department offers information, referrals and assistance for the

elderly and helps them identify community resources that can help with their care, including transportation and nutrition services. It also assesses medical and supportive needs and coordinates a variety of services.

Telephone: Check in the local telephone directory's Blue Pages or in its Government & Municipal Guide.

DisabilityInfo.gov

This government Web site is a one-stop source of information for people with disabilities and their families and contains information on such issues as housing, healthcare, technology, education and employment.

Web site: www.DisabilityInfo.gov

E-Eldercare

This fee-based business provides services nationwide for seniors, including housing location, hygiene assistance, housekeeping, companionship, meal preparation, computer training, transportation, shopping, errands, and home improvements and renovations.

Web site: www.eeldercare.com

The Eldercare Locator

This toll-free directory assistance helps individuals locate aging services nationwide.

Telephone: 800/677-1116, **Web site:** www.eldercare.gov

Family Caregiver Alliance

Nonprofit support organization for caregivers.

Telephone: 415/434-3388, **Web site:** www.caregiver.org

FirstGov for Seniors

This Web site allows seniors to find lots of health information and services at one location 24 hours a day, 7 days a week. Users will be able to access all of the government sites that provide services for senior citizens, and they will be able to do a lot of their tasks (like changing their address) online, rather than going to an agency. **Web site:** www.seniors.gov

Lifeline Personal Response and Support Services

This business provides subscribers with a Personal Help Button that they can wear on their wrist or as a pendant. The subscriber is then able to contact Lifeline staff at any time

by pressing the button. Lifeline assesses the situation and responds accordingly. In addition, the service can also remind subscribers when to take medications, when they have doctor appointments, etc.

Telephone: 800/LIFELINE (543-3546),

Web site: www.lifelinesys.com

Other companies that offer Personal

Emergency Response Systems

Response Link

Telephone: 800/894-1428, **Web site:** www.respondelink.com

Personal Safety Corporation

Telephone: 866/723-2527, **Web site:** www.padalarm.com

Care 24 Incorporated

Telephone: 800/538-9968

Telephone: 800/882-2280, **Web site:** www.lifefone.com

National Alliance for Caregiving

Alliance of companies and organizations that are concerned with family caregiving. **Web site:** www.caregiving.org

National Association for Home Care (NAHC)

The NAHC works to ensure that elderly, chronically ill or disabled people can obtain healthcare and services in their homes so that institutionalization is a last resort. The association provides information on what types of home care services are available, how to find them, how to assess them and how to pay for them.

Web site: www.nahc.org/Consumer/coninfo.html

National Family Caregivers Association (NFCA)

Organization for family caregivers that offers free memberships, a toll-free advisory service, a pharmacy discount program, advocacy and information. **Telephone:** 800/896-3650,

Web site: www.nfcacares.org

National Family Caregiver Support Program

Program that provides information to caregivers about available services, assistance in gaining access to supportive services, individual counseling, support groups, caregiver training, respite care, and supplemental services to complement the care provided by caregivers. **Telephone:** 202/619-0724, **Web site:** www.aoa.gov/prof/aoaprogram/caregiver/caregiver.asp (for information about what is available in a particular state)

SeniorNet

This nonprofit organization offers seniors education about and access to computer technology and the Web.

Web site: www.seniornet.org

Visiting Nurse Associations (VNA)

These community-based, nonprofit organizations provide a range of home care services. **Telephone:** Check in the local telephone directory's Yellow Pages under "Health Agencies" or "Nurses."

Web site: www.vnaa.org

Well Spouse Foundation

A support organization for partners of those with disabilities.

Telephone: 800/838-0879

Web site: www.wellspouse.org