

Caregiver Resources

When a person suffers a traumatic brain injury or a stroke, no one is ever prepared for what is ahead of them. A long road to recovery for the survivor, and a long road for a caregiver.

A caregiver is never prepared for their new role in life. A slew of emotions will hit you all at once. So many questions asked, so many questions unanswered. It's normal to feel overwhelmed, burdened, and even trapped at times while caregiving. Caregivers can often times become depressed and develop physical symptoms, like tiredness and trouble sleeping. Despite the sadness and shock of having a loved one with recover from stroke, many people find personal satisfaction in caring for that person.

So what is a caregiver? We can define a caregiver as the person who most often helps the person with disability and is not paid to do so. Caregivers may be partners, family members, or close friends. Most often, they're not trained for the caregiver job. Many times, they're the lifeline of a stroke survivor.

Caregivers have many roles. These roles change as the patient's needs change during their recovery. With the ever changing insurance rules, many more stroke survivors are being released early from inpatient therapy. This means that more people are being cared for at home still needing an immense amount of therapy for recovery.

Once the survivor is home, the caregiver may have other responsibilities, such as their own children to take care of, their job and maybe even another ailing parent. The economic and emotional tool can be overwhelming.

Roughly 66 percent of all family caregivers are women. The average caregiver is a 49-year-old woman who works outside the home and provides at least 20 hours a week of unpaid care to her aging parent, according to the latest data from the [Family Caregiving Alliance](#).

While men are caregivers, women spend as much as 50 percent more time than men in providing care. Survey data [analyzed by Rich Johnson and Josh Wiener](#) at the Urban Institute found that daughters account for seven out of 10 adult children who help frail parents. Daughters are also five out of every six adult children responsible for the daily, labor-intensive tasks such as feeding, bathing, and dressing that keep their parents out of a nursing home bed.

The work may be unpaid, but it doesn't mean that it's free. Women bear significant financial, emotional, and health costs for being carers, especially if they are also raising children. Caregiving has a significant economic impact on the family – whether it's paying for prescription medications, installing a ramp for a wheelchair-bound parent, or paying for assisted living home expenses not covered by Medicare, private insurance, or long-term health insurance.

More money is needed to cover these expenses. But female, family caregivers often limit their earning potential to take care of their loved one by working fewer hours, passing up job promotions, training and other assignments that lead to career advancement, taking a leave of absence, or switching from full to part-time employment.

So what options are there to help the survivor and the caregiver. Most survivors may be covered by Medicaid or Medicare for home health care services. www.medicare.gov is a great site that will give you information as to what you may be covered for.

Additional help is available for people who have had strokes and their families and caregivers. A good place to start is speaking with your loved ones social worker. They can provide information for local services that will help with recovery.

Some information to look out for is:

Local stroke clubs or other support groups.

These are groups where stroke survivors and family members can share their experiences, help each other solve problems, and expand their social lives.

Home health services.

These are available from the Visiting Nurses Association (VNA), public health departments, hospital home care departments, and private home health agencies. Services may include nursing care, rehabilitation therapies, personal care (for example, help with bathing or dressing), respite care (staying with the stroke survivor so that the caregiver can take a vacation or short break), homemaker services, and other kinds of help.

Meals on Wheels

Hot meals are delivered to the homes of people who cannot easily shop and cook.

Adult day care

People who cannot be completely independent sometimes spend the day at an adult day care center. There they get meals, participate in social activities, and may also get some health care and rehabilitation services.

Transportation services

Most public transportation systems have buses that a person in a wheelchair can board. Some organizations and communities provide

vans to take wheelchair users and others on errands such as shopping or doctor's visits.

Many communities have service organizations that can help. Some free services may be available or fees may be on a "sliding scale" based on income. Again, your social worker will be able to guide you to the right organizations.

There are also other ways outlets in which caregivers can find support. Independent Patient Advocates. [According to the The Alliance of Professional Health Advocates](#), the overall goal of advocates and care managers is to provide patients and caregivers with the support and education they need so they can make their own decisions about their next steps. Whether that is helping to coordinate their care among several providers, sitting by their bedsides to keep them safe in the hospital, helping them interpret difficult medical information and terminology, or reviewing their medical bills to find errors or duplications – the advocate is the one person who has the background and knowledge needed to make the patient's journey as smooth as possible, without the inherent conflict-of-interest that arises within the profit sectors of the system.

The benefit to both patients and caregivers is peace of mind, and the ability to put their efforts toward healing, or supporting their loved one who needs care, knowing a professional is handling the important details.

If you are looking for an Independent Patient Advocate or caregiver, [care.com](#) is a great site to explore.