Respite is a word that means ‘a short break.’ It’s not frequently spoken by stroke families, but it is a word with tremendous meaning for family caregivers.

Though there is still work to do, in recent years, strides have been made to better support the need for respite for family caregivers. Legislation such as the Lifespan Respite Care Act and provisions within the Older Americans Act Reauthorization of 2016 for the National Family Caregiver Support Program have opened opportunities. In many states, family caregivers can now apply for financial support for temporary relief from the ongoing responsibility of caring for an individual with special needs, like post-stroke care.

It’s easy for caregivers of young survivors not to know of this support because the programs are generally managed via state agencies that are focused on aging, such as the Office on Aging, or the Area Agency on Aging. Caregivers of young adults may not be thinking that their needs are related to aging. “There remains an opportunity for us to raise awareness about respite services among young stroke populations,” said Anne Wolf, the community resources divisional manager at the South Carolina Lieutenant Governor’s Office on Aging.

**Legislative Support**

Earlier this year, President Obama signed the Older Americans Act Reauthorization of 2016. Prior to the Act’s reauthorization, there were no provisions for respite support for parents caring for an adult child with disabilities. However, the 2016 reauthorization extends the scope of respite services to now include parents age 55 and older who care for adult children of any age with disabilities.

There may be funding limitations, however. According to information on the Administration for Community Living website, the Act also “clarifies that a state may use not more than 10 percent of the total (federal and nonfederal share) available to the state to provide support services to older-relative caregivers.”

**South Carolina Model**

In South Carolina, the Lieutenant Governor’s Office on Aging partners with the South Carolina Respite Coalition and other local organizations to administer its statewide Lifespan Respite grant program. Caregivers apply for $500 vouchers to compensate respite providers. Funds for the voucher are approved for up to three months and may be renewed annually, though not automatically guaranteed.

“Over the past 18 months, we have awarded six vouchers to family caregivers of midlife stroke survivors,” said Allison Poole, South Carolina Respite Coalition program coordinator. “Caregivers of people in midlife, those folks between the ages of 18 and 60 who need substantial care, are the smallest group from which we receive applications. We know the need is there, but it’s a matter of getting the word out that respite is both necessary for caregivers and available to them.”

“ ‘It’s okay for you to take care of yourself’ is a phrase I repeat to family caregivers to help them open their minds to the idea of receiving help,” said Janet Altman, assistant director of the South Carolina Respite Coalition. “Too often family caregivers attempt to do everything alone. But there
are respite programs to enable them to compensate a trained respite provider to come into their home. This allows them to leave the house to get a haircut, take a day trip, or see a movie with friends while knowing that their loved one is safe and happy.”

What’s available in your state?

Caregivers may benefit from various respite voucher programs available through Area Agencies on Aging in addition to the Lifespan Respite vouchers. Within each state, the Area Agency on Aging has a Family Caregiver Advocate who can assist caregivers with accessing services. Visit Eldercare Locator to find information for your nearest Area Agency on Aging location.

It’s important to keep in mind that even though federal legislation is enacted, program and funding availability varies from state to state. The Access to Respite Care and Help (ARCH) National Respite Network and Resource Center helps families locate respite and crisis care services in their area. Visit their interactive U.S. map to start finding out more about what’s available in your state.

The Family Caregiver Alliance National Center on Caregiving also offers an interactive U.S. map that helps family caregivers locate public, nonprofit and private programs and services nearest their loved one — living at home or in a residential facility. Resources include government health and disability programs, legal resources, disease-specific organizations and more.

TOO YOUNG CAREGIVER

Playful childhood memories of sleeping on the floor of mother Roberta’s hospital room guided the career path of Shanna Hastie, 34.

Throughout Roberta’s life, with the help of her family, she has managed several medical conditions. She has undergone an above-the-knee amputation and receives dialysis treatment. In 1998, at age 40, Roberta had a massive stroke that left her with speech deficits. The following year, Roberta experienced a second stroke that affected the right side of her body. Ten years later, Roberta lapsed into a month-long coma and had a third stroke.

Today, Roberta is 59 and projects a resilient smile and personality. She relies on her daughter and husband Woodrow, 65, as well as extended family and friends, for daily home care.

Several years ago, Shanna earned a graduate degree in Social Work from Clark Atlanta University in Georgia. Like many of the choices in her life, her enrollment there was based on how close the university was to her mother’s home in Sumter, South Carolina. “I’ve always made sure to be within traveling distance,” Shanna said.

Armed with her education credential, Shanna felt especially prepared to deal with the challenge of caregiving. Then, her father experienced a medical crisis resulting in surgeries on his heart and back. Shanna then relocated from Atlanta to Columbia, South Carolina, in 2010 to take care of her parents full time.

During this time, Shanna encountered a confusing web of age restrictions for community resources and medical services. Her father met the age eligibility for eldercare services, but Woodrow required no assistance with personal care. In contrast, her mother recovered with greater dependency after her second stroke at age 42 and was too young to be eligible for eldercare. As a caregiver under 55, Shanna, too, was prohibited access to some services and...
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The pressure you’re putting me under is too much.

I QUIT!

Sincerely,

Your Heart

Don’t let your heart quit on you. If you are living with high blood pressure, just knowing and doing the minimum isn’t enough. Uncontrolled high blood pressure could lead to stroke, heart attack or death.

Get yours to a healthy range before it’s too late. Find out how at heart.org/BloodPressure

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