

The USC Aphasia Laboratory  
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## **Speak Up and Speak Out**

by Amy Edmunds (youngstroke.org)

When stroke leaves a young adult with aphasia, the sudden loss of ability to communicate imposes hardships upon social and workplace relationships which differ from geriatric stroke survivors.

Social relationships are often honed during early adulthood as interpersonal evolve during dating and early marriage. Young adults who experience aphasia may forfeit opportunities to build such meaningful, committed relations due to their inability to effectively express emotions... in addition to managing other deficits imposed by stroke. In contrast, many geriatric survivors have already experienced such relationships. Additionally, many have nurtured long-lasting friendships and raised children into adulthood.

A paramount concern among young stroke survivors is their ability to earn wages. When stroke occurs during the prime years of one's career, aphasia may impose particular challenges for survivors and their employers. Whether one seeks a new job or desires to return to a previous position is often contingent upon their successful performance of oral and written communication skills. Because aphasia presents such a spectrum of deficits, employers are challenged to provide customized accommodations. Geriatric survivors are often less concerned with employment during their retirement years.

Globally, young stroke survivors are an emerging population driven by epidemics of obesity, hypertension and diabetes. Within six years, nearly two million Americans who have suffered a stroke or brain injury will be living with aphasia according to the American Speech-Language Hearing Association. In South Carolina, the Department of Health and Environmental Controls reported 54% of all strokes occurred among those under age 65 in 2012.

There is good news.

Recent research suggest the brain's ability to mend may extend many years post-stroke. Previously, it was assumed speech recovery was limited to less than one year.

There is opportunity.

Such research empowers survivors and caregivers to rally for policy change ... especially among insurers who severely limit the number of allowable rehabilitative services among all stroke survivors. Ironically, this is an issue where the distinction between young and geriatric stroke survivors is most pronounced. If the stroke survivor is over 65, they may qualify for federal assistance provided by Medicare.

But young stroke survivors are not eligible for similar benefits. For example, Blue Cross Blue Shield of South Carolina allows twenty-one rehabilitative services annually. Further, a stroke survivor is allowed a seven day inpatient hospital stay. Typically, a stroke receives three hours

of rehabilitative services each day. These services are comprised an hour each of speech, physical and occupational therapy.

Do the math.

At the end of their weeklong stay, many stroke survivors have already exhausted their allowable insurance benefits. Private pay is too often their only option for continued therapy. Further, private pay is frequently unaffordable for most. “Young stroke survivors are less likely to get post-stroke rehab than older ones ...” stated Ralph Sacco, former president of American Heart Association in 2009 to AARP. In 2012, Katherine Frey of The Washington Post wrote “...the length of formal rehabilitation is largely determined by medical insurance coverage.” In 2014, little differs from five years ago.

This is why it is so important to unite our voices to drive change.

**Amy Edmunds, an ischemic stroke survivor since 2002, is a globally recognized advocate of young adult stroke patients. Her work emphasizes the role of community within the stroke continuum of care.**

YoungStroke, Inc., a 501c3 non-profit advocacy organization, evolved from her graduate research to extend understanding of the stroke experience among young adults and their caregivers.

In 2010, she joined the faculty at Coastal Carolina University and launched its Campus & Community Research Collaborative in 2013.

For more information, visit [www.youngstroke.org](http://www.youngstroke.org) or call 843.655.2835