



# Post Stroke Success Reduces Readmissions

 YoungStroke



Cryptogenic Stroke Survivor since 2002

YoungStroke, Inc. established in 2005

Senior Lecturer of Health Sciences,  
Coastal Carolina University since 2010

Young Stroke Media, LLC established in 2013

World Stroke Organization  
Board of Directors since 2014



# DISCLOSURES

Advisor, Allm EMEA  
since 2017

# OBJECTIVES

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- (1) PSS ... empowers caregivers
- (2) PSS ... removes provider barriers to rehab and educates PCP
- (3) PSS ... implements integrated models of care

# CAREGIVER EMPOWERMENT



**empower  
caregivers  
via education**

**sudden  
change**

# POST-STROKE CHECKLIST (PSC): IMPROVING LIFE AFTER STROKE



This Post-Stroke Checklist (PSC) has been developed to help healthcare professionals identify post-stroke problems amenable to treatment and/or referral. The PSC is a brief and easy-to-use tool, intended for completion with the patient and the help of a caregiver, if necessary. PSC administration provides a standardized approach for the identification of long-term problems in stroke survivors and facilitates appropriate referral for treatment.

## INSTRUCTIONS FOR USE:

Please ask the patient each numbered question and indicate the answer in the "response" section. In general, if the response is NO, update the patient record and review at next assessment. If the response is YES, follow-up with the appropriate action. Please note that the actions described in this version are for guidance and the 'If Yes' and 'If No' text boxes (highlighted in yellow) can and should be edited for local implementation.

1. SECONDARY PREVENTION		
Since your stroke or last assessment, have you received any advice on health related life style changes or medications for preventing another stroke?	<input type="checkbox"/> NO	
	<input type="checkbox"/> YES	Observe Progress
2. ACTIVITIES OF DAILY LIVING (ADL)		
Since your stroke or last assessment, are you finding it <b>more</b> difficult to take care of yourself?	<input type="checkbox"/> NO	Observe Progress
	<input type="checkbox"/> YES	Do you have difficulty dressing, washing and/or bathing? Do you have difficulty preparing hot drinks and/or meals? Do you have difficulty getting outside?
3. MOBILITY		
Since your stroke or last assessment, are you finding it <b>more</b> difficult to walk or move safely from bed to chair?	<input type="checkbox"/> NO	Observe Progress
	<input type="checkbox"/> YES	Are you continuing to receive rehabilitation therapy?
4. SPASTICITY		
Since your stroke or last assessment, do you have <b>increasing</b> stiffness in your arms, hands, and/or legs?	<input type="checkbox"/> NO	Observe Progress
	<input type="checkbox"/> YES	Is this interfering with activities of daily living, sleep or causing pain?



**annual  
assessments  
post-stroke  
checklist**

# CAREGIVER RESPITE



Portrait of survivor Amy Edmunds courtesy of Paul A. Olson

StrokeConnection

## Respite: Because You Care

By Amy Edmunds, Survivor;  
Founder and CEO, YoungStroke Inc.  
Conway, South Carolina

**R**espite 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

# Virginia's Family Caregiver Support Program

- Individuals eligible for respite care under this program are:
- Family caregivers **providing care for individuals age 60 or older**;
- Family caregivers providing care for individuals with Alzheimer's disease and related disorders, regardless of age; or
- Grandparents and other relative **caregivers (not parents) 55 years of age and older** providing care to children under age 18; or
- Grandparents, parents and other relative **caregivers 55 years of age and older** providing care to adults ages 18-59, with disabilities, to whom they are related by blood, marriage, or adoption.
- Tribal Organizations can set a lower age than 60 for members to be considered as elders eligible for services.

# REHABILITATION



# ECONOMIC BURDEN

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## Unexpected Expenses

Things to consider as you're working on recovery

By Amy Edmunds, Survivor;  
Founder and CEO, YoungStroke Inc.  
Conway, South Carolina



Portrait of survivor Amy Edmunds courtesy of Paul A. Olson

**S**troke in young adults can bring on money troubles that may be as challenging as the recovery itself.

"All patients, regardless of their insurance type, can have large medical expenses they are required to pay after their insurance has paid its portion," said Erin Singleton, chief of mission delivery at the Patient Advocate Foundation (PAF). "Unlike other forms of debt, medical debt arises unexpectedly and is compounded by a decrease in income resulting from missed work either by themselves or those who act as a caregiver."

With guidance, good choices for weathering stroke's impact on your budget are possible. Here are some examples and guidance from others who've been there.



**MEET ANN MARIE AND ROB**  
Hilton Head, South Carolina

Ann Marie, 50, awoke at 2:30 one morning last year to find her husband having an ischemic stroke. Rob, 51, had no history of high blood pressure or cholesterol and had always been physically active. His stroke was caused by a tear in his carotid artery. Rob's stroke left him with aphasia and unable to walk. His long-term effects include limited

speech and writing ability, foot drop and memory loss. He also lost use of his right arm. Rob had just finished his memoir before his stroke left him unable to write a complete sentence.

Previously, Rob had been an accomplished lieutenant aboard a nuclear submarine, followed by service at the Pentagon. More recently, he retired as a consultant for a management consulting firm.

Rob was semi-retired at the time of his stroke, but he and Ann Marie felt sure they were adequately insured to offset medical needs. They were sorely mistaken.

"I never imagined my insurance coverage would not pay for Rob to get better," Ann Marie said. "When we purchased our medical coverage, I recall we were told that we would be covered 100 percent after paying our premiums and meeting the \$5,200 deductible. Like many others, we didn't think about rehabilitation."

Rob needed more rehab than the 21 annual visits their insurance provided, and Ann Marie wanted him to have additional therapy. "How fortunate we are that I was previously a nurse," Ann Marie said. "At least I have the confidence to seek resources and to research options."

When combined with the cost of medications, durable medical equipment and in-home care, the cost of this extra therapy was significant. And Ann Marie and Rob aren't taking care of just themselves. They also have a 20-year-old son, Eliot, at Clemson University and their 15-year-old daughter, Emily, is living at home.

They also have two adult sons who are financially independent. Based on their experience with Rob's stroke, Ann Marie now encourages both sons to understand the specifics of the insurance coverage offered by their employers. "They believe



**United  
States  
2009**

Young stroke survivors  
are less likely  
to get post-stroke  
rehab  
than older ones ....”

Ralph Sacco, M.D.,  
Former President of American  
Heart Association/ American  
Stroke Association

**pcp education  
about  
late onset  
deficits**

# UNTREATED SPASTICITY


4X

healthcare cost

**compared with stroke survivors without spasticity.**

Source: Lundstrom et al. Stroke 2010; 41(2):319-324.





# INTEGRATED MODELS OF CARE



# PennState Health

Milton S. Hershey Medical Center



## SOURCE:

Emerg Med J. 2018 Jun;35(6):372-378.

doi: 10.1136/emered-2017-207211.

Epub 2018 Apr 17.

Development of sustainable community paramedicine programmes: a case study in Pennsylvania.

- Trained in NIHSS assessment
- **Home visit within 5 days of discharge after meet during hospital stay**
- Component of discharge care plan, no additional cost



# COMPASS

COMPREHENSIVE POST-ACUTE STROKE SERVICES



## Cheryl Bushnell, MD Wake Forest

COMPASS Care Plan™  
integrated with a  
**community-specific  
resource database**

# Roger C. Peace Rehabilitation Hospital Greenville, South Carolina



- **Services include:**
- Neuropsychological screening
- Comprehensive neuropsychological assessment
- Psychological consultation and evaluation
- **Individual, family and group psychotherapy**

**stroke is  
more than  
a medical  
diagnosis**

# COMMUNITY INTEGRATION





**Join our great  
work today ...**

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