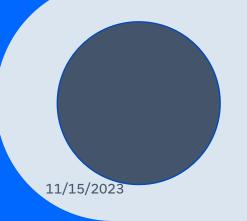
Stroke Beyond the Hospital

Transitions of care and Post Stroke Recovery Resources

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Stroke Advocate



Disclosures

The presenter has no relevant financial relationship to disclose.



Disclaimer

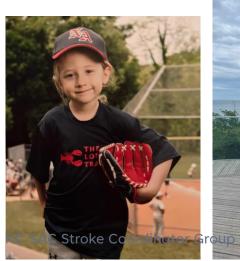
Former Stroke Program Manager Mission Health – Retired July 2022

United Stroke Alliance Board of Directors/Camp Director Volunteer

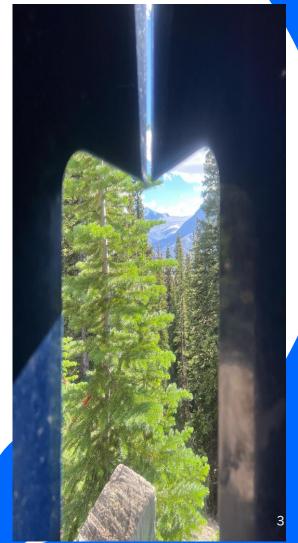
Member of North Carolina Stroke Advisory Council

Global traveler

And Baxter's Nonni





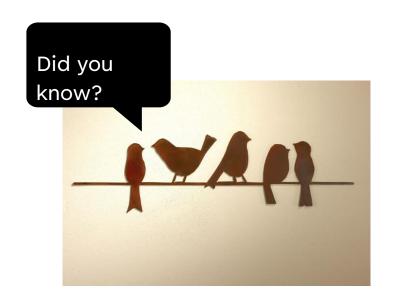


Objectives

By the end of the presentation, you will be able to:

- -Identify best practices in post stroke transitions of care
- -Discuss the benefits of stroke camp for survivors and caregivers
- -List post-stroke resources
- -Support advocacy for stroke survivors and caregivers

My goal is that you will hear something today that you feel compelled to pass on!





It's so much more

The past 45 years my career was mainly in the acute hospital

I was on the front line experiencing the transformation of acute stroke care working in Emergency nursing and Neuro critical care.

It wasn't until I started working with stroke survivors and caregivers that I realized that "we didn't know what we didn't know"?!



I would like to dedicate today's presentation to some of my Stroke Heroes















Transitions of Care

The term "transitions of care" is broader than clinical handover because it encompasses the clinical aspects of care transfer and other factors, such as the views, experiences and needs of the patient.

WHO Technical Series on Safer Primary Care

On average a stroke patient will make 3 transitions of care from the hospital to home. Some have as many as 7 transitions.



Care Transition Interventions to Improve Stroke Outcomes

The majority of a stroke patient's recovery occurs **AFTER** hospital discharge, and therefore, is directly affected by the quality of care provided during the transitional care period.

Issues raised included:

- Poor access to rehabilitation resources,
- wide range of unmet needs,
- educational and informational challenges, and
- poor medication adherence

Care Transition Interventions to Improve Stroke Outcomes: Evidence Gaps in Underserved and Minority Populations | Stroke (ahajournals.org)



Transitions are high-risk for patient safety

The impacts of problems identified at the primary care interface(s) in the literature include:

- increase in mortality
- increase in morbidity (temporary or permanent injury or disability)
- increase in adverse events
- delays in receiving appropriate treatment and community support
- additional primary care or emergency department visits
- additional or duplicated tests or tests lost to follow-up
- preventable readmissions to hospital
- emotional and physical pain and suffering for service users, carers and families
- patient and provider dissatisfaction with care coordination

WHO Technical Series on Safer Primary Care



Care Transition Interventions to Improve Stroke Outcomes

Review including evidence gaps in underserved and minority populations



Persons returning home after stroke have unmet needs. We don't know the best way to support patients and caregivers during this transition.



Vulnerable and minority populations have greater needs, poorer outcomes & access to fewer resources



To advance the field we recommend:

- Community-based participatory research that engages with vulnerable or minority populations.
- Ensure interventions are co-designed with members of the target population.



 Develop and test eHealth solutions: identify the advantages and disadvantages of using them in vulnerable, underserved and minority groups.



- Ensure interventions last sufficiently long to help patients.
- Provide transparent reporting of study methods. Measure outcomes that are important to patients.



Mathew J. Reeves. Stroke. Care Transition Interventions to Improve Stroke Outcomes: Evidence Gaps in Underserved and Minority Populations, Volume: 54, Issue: 2, Pages: 386-395, DOI: (10.1161/STROKEAHA.122.039565)

Nursing's Role in Successful Stroke Care Transitions Across the Continuum: From Acute Care Into the Community

Michelle Camicia, Barbara Lutz, Debbie Summers, Lynn Klassman, Stephanie Vaughn

Nurses have been identified as key stakeholders and team members in a comprehensive stroke system of care.

Stroke coordinators have been at the helm of the advances we have seen in acute stroke care.... reducing DTN, interventional thrombectomy, telestroke... you have made the difference.

Similar advances stroke care transitions in the postacute and return to community phases have lagged behind.



Recommendations to optimize safe, effective, and efficient care transitions for stroke survivors and their family caregivers

- Establish a system of coordinated and seamless comprehensive stroke care across the continuum of and into the community;
- 2. Implement a stroke nurse liaison role that provides consultant case management for the episode of care across all settings/services for improved consistency, communication and follow-up care;

Recommendations to optimize safe, effective, and efficient care transitions for stroke survivors and their family caregivers

- 3. Implement a validated caregiver assessment tool to systematically assess gaps in caregiver preparedness and develop a tailored caregiver/family care plan that can be implemented to improve caregiver preparedness;
- 4. Use evidence-based teaching and communication methods to optimize stroke survivor/caregiver learning, and
- 5. Use technology to advance stroke nursing care.



Nursing's Role in Successful Stroke Care Transitions Across the Continuum: From Acute Care Into the Community

Current state: stroke nurse navigators help guide stroke patients and their families through the acute care trajectory.

However, these navigators are typically limited to the acute phase of care.



Life After the Stroke

Approximately 52% of stroke survivors are discharged from acute care to inpatient PAC to IRF or SNF (~24% to IRF 27% to SNF)

Although insurance and geographic factors have been shown to impact the selection of a PAC setting following stroke, nurses have a significant influence on this decision.

It is essential that stroke nurses in the acute care setting understand the PAC delivery system so that they can provide the stroke survivor and family education on scope and intensity of PAC services.

With knowledge comes understanding

It is important to build relationships among care professionals to increase the understanding of each other's roles across settings.



An integrated health system implemented a QI educational program for acute care nurses on-site at IRF to provide information about programs and services offered at the IRF level of care, admission criteria and how their documentation influences the patient meeting IRF admission criteria. This resulted in better understanding by acute care nurses of IRF.



Stroke PAC recommendations

AHA recommends that stroke survivors with impairments receive organized, coordinated, interprofessional care at the IRF level of care.

When compared with SNFs, stroke survivors who are treated in an IRF are more likely to be discharged to the community, and hospital readmissions are lower, with similar outcomes for allcause mortality.

Patients admitted to IRFs have greater improvement in mobility, self-care, and cognition.

The Association of Rehabilitation Nurses has a detailed description of the PAC settings available at https://rehabnurse.org/uploads/membership/ARN_Care_Tran-sitions-Levels_of_Care.pdf



Transition to Home

The discharge transition from the inpatient setting to the home and community is one of the most vulnerable and significant events in the continuum of care for stroke survivors and their families.

How many times have you heard patients and especially caregivers state they did not feel prepared for what was to come?



Evidence-based models for transitions of care

- Early supported discharge,
- Predischarge home visits,
- Identification of barriers to transition,
- Comprehensive stroke education,
- Discharge checklists and
- Community Networks





Here are your discharge instructions... any questions?

"In Stroke's Shadow: My Caregiver Story"

"As a caregiver, I've had to put my life and my goals on hold for now. From all the blogs and pages you read about caregivers, it's hard. It's a hard road. It's very tiring. But do you want this or do you want to not have your spouse with you? So I'd rather be tired."



41,994 likes

nytimes Around 53 million Americans are caregivers for a family member or friend with a health issue or disability, and nearly a third spend 20 or more hours a week in that role. Looking after a sick family member can mean putting your own life on hold, often with little recognition or outside support.

The Centers for Disease Control and Prevention, which calls caregivers the "backbone" of long-term home care in the U.S., has warned that caregivers face many risks, including anxiety, depression, chronic health conditions and financial strain. Yet experts said that many caregivers feel they cannot speak openly about their frustration and anger, and that it is important to normalize those feelings.

Read more about the quiet rage of caregivers — and how some seek community support — at the link in our bio.

PATH-s assessment tool

The Preparedness Assessment for the Transition Home after Stroke (PATH-s) instrument was developed by Michelle Camicia and Barbara Lutz in response to the ARN White Paper, "The Essential Role of the Rehabilitation Nurse in Facilitating Care Transitions" (Camicia et al., 2014).

25-item self-administered clinical assessment of caregivers developed to assess caregivers' commitment and capacity prior to IRF discharge, before they have assumed the caregiving role

PATH-s Instrument | ARN (rehabnurse.org)



PATH-s Sample question

- 4. How much do you understand about what assistance the stroke survivor will need with personal care (such as bathing, using the toilet, dressing, and moving around) when he/she goes home?
 - I do not understand what assistance the stroke survivor will need with personal care when he/she goes home.
 (1)
 - I <u>understand a little</u> about what assistance the stroke survivor will need with personal care when he/she goes home. (2)
 - I <u>understand some</u> about what assistance the stroke survivor will need with personal care when he/she goes home. (3)
 - I <u>understand a lot</u> about what assistance the stroke survivor will need with personal care when he/she goes home. (4)





ASSESSING FAMILY CAREGIVERS USING THE PATH-S INSTRUMENT

OVERVIEW

FACULTY

ACCREDITATION

REGISTER/TAKE COURSE

This is an on-demand webinar that was recorded on a previous date. The webinar is about 1 hour in length. You will need to watch the webinar, receive a 70% or higher passing grade on a quiz, and then complete an evaluation to receive your certificate and complete this course. You will have access to this course for 1 year, starting on the purchase date.

Family caregivers are central to successful discharge home for patients receiving inpatient rehabilitation services; yet their needs and concerns are often not assessed. Completing and documenting a comprehensive caregiver assessment has become a national priority.

In this webinar, Dr. Camicia and Dr. Lutz will describe the background, theoretical basis, and development of the Preparedness Assessment for the Transition Home after stroke (PATH-s) tool. Strategies for implementation in inpatient rehabilitation facilities will be discussed.

Examples of successful integration of the PATH-s tool in the clinical setting will be described.

Available credit: 1.25 CNE Publication date: 03/15/2021 Purchase deadline: 06/17/2024 Member cost: \$0.00 Non-member cost: \$0.00 Rating:

LEARNING OBJECTIVES

- Recognize the importance of assessing caregiver preparedness
- Understand the theoretical foundation for the PATH-s instrument
- Identify strategies for administration of the PATH-s instrument

Assessing Family Caregivers using the PATH-s Instrument | ARN Learning Center (rehabnurse.org)







Together to End Stroke

Leaving the hospital after your stroke can be scary and overwhelming. To help you prepare for what's next in your recovery, hospital staff will speak with you and the person helping to care for you about what you can expect. Use the checklist below to help guide your conversations and to make sure your questions are answered.

INSTRUCTIONS:

- 1. You and the loved ones helping you should talk with your medical staff throughout your stay about the questions below.
- Check the questions that you have asked and have gotten answers for, skip any that aren't applicable. Make sure you fully understand the answer before checking the box.
- Write down the answers to your questions and any important information (e.g., names, phone numbers, etc.) in the spaces that follow.
- Bring the checklist home and make copies for friends and family who may help you with your post-stroke care.

Questions to facilitate the discharge plan

What tasks will I need help with? Can you show my caregiver how to
do the tasks that require special skills?
If you can't answer these questions yet, who will I talk to who can
help answer them?

https://www.stroke.org/-/media/stroke-files/stroke-resource-center/recovery/patient-focused/stroke-discharge-list-for-patients-and-caregivers-ucm_463810.pdf

Do any of you use these tools for acute care discharge to home?

How does your team assess the caregiver's readiness for discharge?

Data drives Change... we need research in this arena!



Stroke Peer Volunteers



As we bring to a close National Stroke Awareness Month, we'd like to recognize two of our Stroke Peer Volunteer champions. Meet John, Mission Health's Stroke Peer Volunteer (left), and Robert, Mission's Stroke Peer Chaplain Volunteer (right). Both work exclusively with the stroke program to enhance the stay of stroke patients by visiting with them and their support person(s), sharing experiences as stroke survivors themselves and providing a listening ear and encouragement.... See more





Stroke survivors serve as Stroke Peer Volunteers and make rounds on the identified stroke patients prior to patient discharge.

"Street cred"

"I hear you"

"I can identify"

Both are very active in the local stroke support group and felt the "call" to do more.

Stroke Support Groups

"Peer support groups play an important role in stroke recovery by providing tools for effective coping, alleviating psychological stress, and creating an outlet for stroke survivors and caregivers."



Have you or someone you love experienced a stroke?

YOU'RE NOT ALONE.



Table 1. Resources for Nurses

National Transition of Care Checklist: https://static1.squarespace.com/static/5d48b6eb75823b00016db708/t/5d49bc833b48f80001f154bc/1565113475856/TOC_Checklist.pdf

Patient Education Materials Assessment Tool: https://www.ahrq.gov/health-literacy/patient-education/pemat.html

Teach-Back Method: https://www.ahrq.gov/patient-safety/reports/engage/interventions/teachback.html

Preparedness Assessment for the Transition Home After Stroke: www. rehabnurse.org/pathtool

Prehospital/EMS: https://www.heart.org/en/professional/quality-improve-ment/mission-lifeline/mission-lifeline-stroke

ASA Resource Library: https://www.stroke.org/en/professionals/stroke-resource-library

AHA Acute Ischemic Stroke Healthcare Professional Resources: https://www.stroke.org/en/professionals/stroke-resource-library/acute-ischemic-stroke-healthcare-professional-resource-page

Heart and Stroke Foundation of Canada: https://www.strokebestpractices.ca/resources/professional-resources

World Stroke Organization: https://www.world-stroke.org/professional

Stroke Certified Registered Nurse: https://abnncertification.org/scrn/about

Certified Registered Neuroscience Nurse: https://abnncertification.org/ cnrn/about

Certified Registered Rehabilitation Nurse: https://rehabnurse.org/crrn-certification/crrn-certification

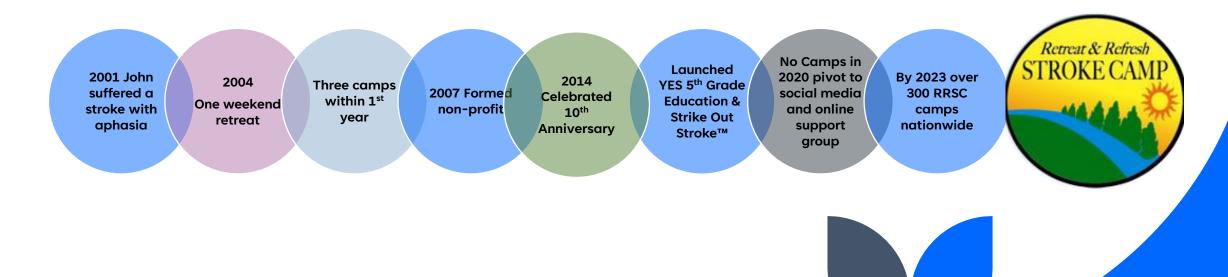


Life After the Stroke

....in 2013 while attending AANN national conference... I met the leaders of Retreat & Refresh Stroke Camp and I knew I had to make this available for my patients and caregivers

"I never set out to change the world"

Marylee Nunley cofounder of RRSC



Stroke Survivors & Caregivers

Two out of three patients survive their first stroke, but many are left with long term disability and consequent needs for health care

One of the most profound consequences of stroke survivors, their caregivers and families is communication impairment

Together with stroke survivors, caregivers require information and long-term practical, emotional, social and financial support

At six months post-stroke approximately one-third to one-half of stroke survivors will be depressed

Three-year changes were studied among family caregivers of REGARDS participants who experienced a stroke event – For leisure satisfaction, differences were still significant at 36 months post stroke

Haley WE, Roth DL, Hovater M, Clay OJ. Long-term impact of stroke on family caregiver well-being: a population-based case-control study. Neurology. 2015 Mar 31;84(13):1323-9



32

Unmet needs

- In a survey among 391 stroke survivors, the vast majority (87%) **reported unmet needs in at least 1 of 5 domains** (activities and participation, environmental factors, body functions, postacute care, and secondary prevention).
 - Depression and receipt of community services after stroke were associated with more unmet needs.
- Patients with stroke are at increased risk of depression. Approximately one-third of stroke survivors develop poststroke depression, and the frequency is highest in the first year after a stroke.
- In a secondary analysis of a randomized, multicenter, placebo-controlled trial among 308 patients with spontaneous intracranial hemorrhage, poststroke depression occurred in 36% of patients at 180 days.
- A meta-analysis of 12 studies that included 1756 caregivers, the pooled **prevalence of depressive** symptoms among caregivers was 40. Symptoms of anxiety were present in 21%

Heart Disease and Stroke Statistics – 2023 Update: Circulation. 2023; 147:e93-e621.

The continuum of connectedness and social isolation during post stroke recovery

During stroke recovery, individuals experience changes related to connectedness with others or **becoming isolated from others**. These experiences are an important part of the psychosocial dimensions of their health.

Changes in connectedness for veterans' post stroke were **examined across 12 months** following discharge home using the continuum of characteristics of connectedness and social isolation. Post-stroke, **many participants were at risk of experiencing isolation**.

Results suggest **nearly half of stroke survivors experienced isolation post stroke**; these findings are supported through participant narratives.

Jolie, et al. "The Continuum of Connectedness and Social Isolation during Post Stroke Recovery." Journal of Aging Studies, JAI, 10 Jan. 2008,

Hope Post-Stroke: Stories of Resilience and Determination from the Stroke Survivor Community

A social media campaign that featured stroke survivors' stories organizations involved included MedRhythms, Stroke Buddies, Stroke Onward, The Brain Injury Hope Network, and Aphasia Nation.

What kind of stroke did you have and when did it occur?

What is a challenge you experienced and overcame during your stroke recovery?

If you could go back in time to when you had your stroke and you could give yourself one piece of advice, what would that advice be?

Why is it important to have hope in the recovery process?

Is there anything else you'd like to share?

Perseverance and patience

Common theme was the <u>importance of perseverance and patience</u> while challenging oneself to not give up in the face of difficulty during the recovery process.

If she could go back in time to when she had her stroke and share one piece of advice, it would be that "patience and consistency is the most important gift of healing."

In addition to the power of perseverance, many of the stroke survivors who shared their stories with us focused on the **power of neuroplasticity.**

"All we have is hope," said Neal, a stroke survivor who had an ischemic stroke in 2017, "and as long as there is neuroplasticity, I will keep trying to improve."

Belief

"It is hope that keeps us from falling into despair, where we remain stagnant"

 This guidance of hope, whether it comes from small successes or trust in the complexity of neuroplasticity, is what can propel the healing process forward, both physically and emotionally.

"Now hope that is seen is not hope. For who hopes for what is seen? But if we hope for what we do not see we wait for it in patience." Romans 8:24





The mission of RRSC is to improve the quality of life for stroke survivors, caregivers, and their families.

Socialization

Relaxation

Education

Support











RRSC – turnkey operation

United Stroke Alliance/RRSC provides the infrastructure – theme, skits, supplies, staff and music therapist

The sponsor(s) provide the funding, the volunteers and recruit campers

Two & half day weekend retreat

Location and accommodations are handicap accessible

Cost to sponsor organization \$23,000

Covers cost of lodging, food, music therapist, supplies, 4 staff members to work your camp

RRSC does all the contracts, negotiations, reservations

Campers and Volunteers register on line (also have paper form if needed – just call their toll free number) www.strokecamp.org

Cap off campers at 40 (includes survivors and caregivers)

Camper fee \$150 ** hardship scholarships available

Volunteers commit to entire time (limit to 15)

Music is integral to the entire weekend

- Music therapist come from a variety of settings but all are trained/certified and are integral to the weekend activities
- Providing opening and closing "music circles"
- Lead singing at campfire and for other activities
- Recruit survivors to sing at Saturday night "show"
- https://medrhythms.com/





Skits including all the props and songs! This group prepares to represent France

Maureen Mathews et al, conducted surveys in 2008 – 2012 The results were presented in poster and lecture form at ISC and published in AHA/ASA publications ⁶

Background:

Depression, loneliness and social isolation are common characteristics of stroke survivors and caregivers

Limited stroke camps are available in the country and there is limited data on effects of a camp experience on emotional status of survivors and caregivers

Mathews M, et al., Stroke Camp offers emotional and physical relief for Stroke Caregivers. 2016 ISC abstract 27

Results: Caregiver/survivor losses

independence,

speech,

driving,

job,

socializing,

family,

friends,

future goals,

multi-tasking,

comprehension,

control,

physical/emotional

companionship,

confidence,

secure retirement,

general independence

Conclusions

Stroke Camp has had a positive impact on both survivors and caregivers

Although survivor and caregivers acknowledge the importance of family/friends, both groups felt they had these supports

97% think a camp experience will be helpful to others

The camp environment with others who share a similar experience may help alleviate feelings of depression, isolation and loneliness in these individuals who have experienced a life changing event

85% of survivors in 2010 indicated camp experience made them feel less alone



Survivor: "We felt normal for a change and comfortable – very hard to express how great it was"

Caregiver: "This is the most that I have smiled and laughed since November 2021 (date of my husband's stroke)."

"If I had to send a message to people who are not familiar with stroke or professionals who only deal with the clinical aspect of stroke, it would be to never put the "stroke" ahead of individual. Understand that we all have something to offer one another."

Joey DPT student volunteer





























Stroke Camp "Sparks"

United Stroke Alliance/RRSC facebook live

Nebraska Stroke Camp Facebook Group

Kansas Stroke Foundation https://www.facebook.com/kansasstrokecamp

Stroke Buddies online support group https://www.facebook.com/groups/strokebuddies

Stroke Peer Visitation Program

Chimes Choir

Stronger Than A Stroke – Anytime Fitness program

Med Rhythms https://medrhythms.com/

Know Stroke Podcast https://www.knowstrokepod.com/podcast

Aphasia Nation https://aphasianation.org/



From a single weekend stroke caregiver and survivor retreat to a...

6/26/2023 | 73 min

Can the brain heal itself after a stroke?



"We didn't know what we didn't know"

Neurogenesis: the brain's ability to create new brain cells

Neuroplasticity: the brain's ability to rewire pathways

Rehabilitation therapies stimulate sprouting of existing nerve cells, causing them to make connections to other nerve cells. The brain can recruit surviving parts to take over the functions of the damaged areas

The best outcomes are seen when rehabilitation is started early in the recovery phase.

Post Stroke Resources

Not a complete list!



NEUROLOGIC MUSIC THERAPY® Music. It's Science.

MedRhythms is a neuro-rehab company that exists to restore the lives and quality of life of loved ones, which brain injury threatens to steal each year. We do this through world-class, life changing care for those afflicted by neurologic injury or disease, using the power of Neurologic Music Therapy.

MedRhythms focuses on this intersection between music, neuroscience, and technology, providing interventions to achieve optimum outcomes in sensorimotor, speech & language, and cognitive goals in patients.

MedRhythms Therapy

Therapeutic Singing

https://youtu.be/EK5qqYYxjn4

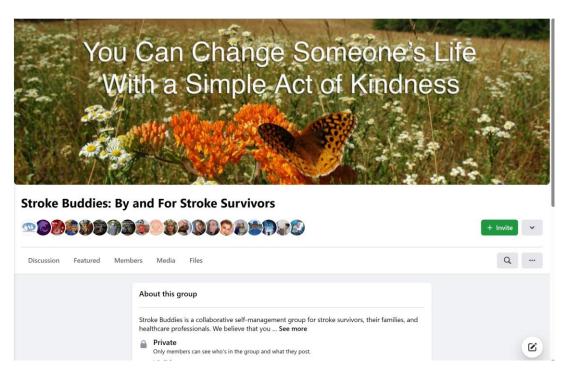
When we met Peter, he had suffered a stroke, leaving him unable to speak.

Know Stroke Podcast

Learn More About Mike and David's "Why"
Listen to the first "Let's Know Stroke" Podcast Episode



Stroke Buddies Virtual Support Group





stroke buddies - YouTube



Spokes Fighting Strokes

Road To hope, freedom, and recovery!

Our mission is to reach every stroke survivor and show them that recovery is possible! Through Adaptive Cycling clinics we help stroke survivors to get their life back, by regaining strength and ability, hope and freedom. The goal is to increase awareness about stroke and HHT (Hereditary Hemorrhagic Telangiectasia), and to make Adaptive Cycling available to the stroke community.

A person can overcome the effects of a stroke to lead a positive, productive life. I would like to ride with stroke and brain injury survivors one or two days a week and show them how easy it can be.



"Focus on your abilities, not your disabilities"

Home | Spokes Fighting Strokes



Believe Stroke Recovery Foundation

Mission

To provide stroke and brain injury survivors with financial assistance and resources to help them better control and manage their journey to recovery.

Goal

To provide support to stroke and other brain injury survivors with inadequate health insurance coverage so that they can benefit from rehabilitation therapy, equipment and continued care to aide in an optimal recovery.

Vision

We BELIEVE that with patience, perseverance and proper support, the journey to an optimal stroke or brain injury recovery is possible. Believe you can, because we do!



Internet Resources

- American Stroke Association <u>www.stroke.org</u>
- American Stroke Foundation https://americanstroke.org
- Aphasia Nation without borders https://aphasianation.org
- Believe Stroke Recovery Foundation <u>www.believesrf.org</u>
- Brain Aneurysm Foundation <u>www.bafound.org</u>
- Know Stroke Podcast <u>www.know-stroke.org/knowstrokepodcast</u>
- NC Heart Disease and Stroke Prevention <u>www.startwithyourheart.org</u>
- Stroke Buddies Virtual support group https://strokebuddies.org/
- Spokes Fighting Strokes https://www.spokesfightingstrokes.org/
- United Stroke Alliance <u>www.unitedstrokealliance.org</u>
- World Stroke Organization <u>www.world-stroke.org</u>

"Doc Tierney taught his son that treatment is the easy part of medicine; the real challenge is getting the diagnosis right And the key to the right diagnosis, he would say, comes from really listening to the patient"

Tim Russert

Big Russ & Me Father and Son Lessons of Life

Passion

A small group of thoughtful people (*like you*) could change the (*stroke*) world. Indeed, it's the only thing that ever has.

Margaret Mead



Stroke Buddies: By and For Stroke Survivors

Thank you

Robin Jones

robinncrn@live.com



Retreat and Refresh Stroke Camp

https://youtu.be/7_4jAKAJsB4

