



# Stroke Support Groups:

Starting and maintaining a group during and post-pandemic

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Upstate Comprehensive Stroke Center- RUSH Lecture Series

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# Key points

-The CNY Experience  
SUPPORT GROUP BASICS

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MODELS, Mission &  
GROUNDWORK

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VIRTUAL LANDSCAPE

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RESOURCES: AHA

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OTHER CONSIDERATIONS

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AT THE HEART

# CNY Stroke Support Group – kudos to Carrie

Currently meets monthly, virtually with 2 meetings per year in person – May for stroke awareness month celebration and December for a holiday gathering

Carrie Garcia, SLP- founder and heart of our CNY Stroke Support Group – One “woman show” –great example, great resource

Successful group in CNY since 2015 – **8 Years!**

Up to 15 active members pre COVID

Recruited – so many colleagues and community members to speak to our group on a range topics from traditional therapies to latest in scientific research on robotics from SU! (including today’s talk also) ☺

*Creativity: Crafts, Live Music, Reiki, Yoga, Dance, Poetry as a tool by SLP...*



# Support Group – “Duh’s”

## Why have one for stroke survivors and caregivers ?

### Needed now more than ever

- AHA ASA and state level push on Post stroke care and programming
- High stress environments and Isolation post pandemic
- Younger onset of strokes
- State of healthcare staffing may allow for only the necessities at discharge
- Post stroke depression is REAL

### Benefits can be instant-

- Positive effects after just one meeting
- Life changing potential for survivors and caregivers

### Integral to optimal stroke recovery journey

- Recovery work is forever
- Allows for real connections vs email or other unofficial forums
- Reduces isolation

### Hospital or facility based

- Experts readily available beyond leaders and facilitators
- Win-win for all



# Models and Missions of Stroke Support Groups

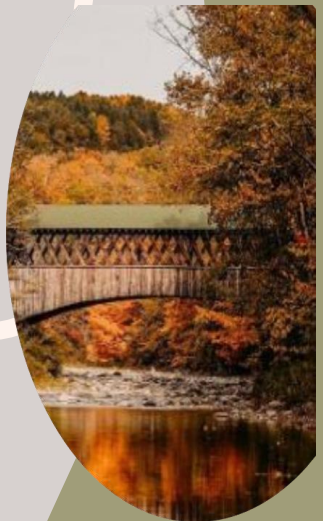
Self Help Support Group- Peer support Groups -

Professionally Operated: Licensed or professionals in that field act as facilitators and manage group's needs.

→ Curriculum based or topic focused

“A support group among people with shared experiences may function as a **bridge** between medical and emotional needs.”

– Mayo Clinic staff



# Tips we have learned:

## Set your groundwork & expectations

- Design a schedule that works for most (time of day) & develop a simple mission
- Review schedule, articulate the mission to the group, at start of meeting-reminders are good
- Develop a mode of communication – email, or webpage or both
- Keep communication regular – articles, events, community resources
- Not group therapy
- Not a one man/woman “show” –try to engage everyone
- Pay attention to “group development” as people join and leave – dynamic



# Tips we have learned: In person to virtual – COVID years

- In person meetings – transportation challenges
- Meeting space challenges –parking and other logistics
- Technology- stroke deficits & learning curve
- Losing members when moving to virtual
- Be flexible – roll with it
- Need to reach survivors from all sources  
(therapy, stroke clinic, PCP, church etc.)



## VIRTUAL MEETINGS: VIA ZOOM OR ANOTHER PLATFORM: THE GOOD AND NOT SO GOOD

### Good

- Attendance may be easier (mobility issues) and more regular
- Survivor can listen and caregiver can do other things
- Can place restrictions for security (only host lets in)
- May reach more people
- Can use chat for questions and comments

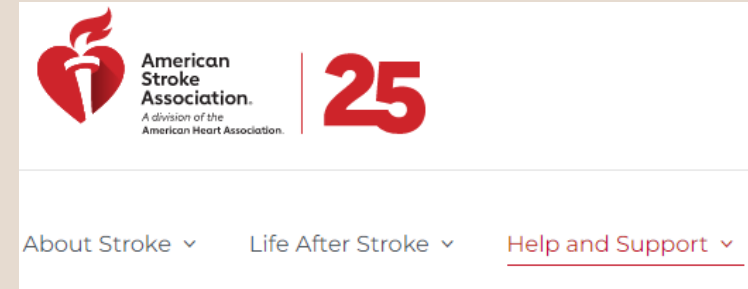


### Not so good

- “Technical difficulties” —waste time/frustrating especially on first meeting
- Listening but no camera
- Difficult to assess body language
- Difficult to convey emotion, makes word choice so important
- Stroke deficits make extended screen time difficult
- Controlling “monologues” difficult to interject



# Resources: did you know?



- AHA – American Heart Association Help and Support
  - Support Group Leader Resources
  - Starting a support group
  - Lesson Modules- 8 pre-developed modules includes presentation and discussion guide
    - Preventing another stroke, pseudo-bulbar effect, incontinence, post stroke depression, personality changes after stroke, post stroke pain, managing spasticity and managing medications
  - Suggestions for groups: special occasions, or breakout groups (aphasia)
  - Register your group : i.e., “snowbirds” can join in a new location
- Long Beach CA- Stroke Support Association – been meeting since 1980! Good website example  
<https://strokesupportassoc.org/our-services/support-groups/>

# Other Considerations:

- Poll group for topics they want
- Call on resources outside the affiliated facility- For example: Hope for the Bereaved, County Departments of Health
- Logistics: develop Co-Leaders and report back to each other
- Facilitators who are therapists (PT, OT, SLP) is a very strong model
- “Phone a mental health friend” or get training in therapeutic communication methods as needed – study Grief and Loss
- Learn when to reach out personally to members
- Market your group - lobby for presenters, help everywhere you go!
- LAUGH whenever possible! Build it into the meetings
- SHARE and NETWORK

# Stroke Camp 2023 – Weekend Retreat



The poster is for the 'WEEKEND RETREAT' organized by the 'Retreat & Refresh STROKE CAMP', which is a division of the 'UNITED STROKE ALLIANCE'. It features a 'TV LAND' logo and mentions 'featuring our theme'. The event is a 'fun-filled weekend retreat created with stroke survivors and caregivers in mind'. The dates are 'August 4-6, 2023' at 'LeTourneau Christian Camp, Rushville, NY'. A QR code is provided for registration, with a cost of '\$150 (all inclusive)'. Activities listed include 'CRAFTS', 'EDUCATION', 'PAMPERING', 'DISCUSSIONS', 'GAMES', and 'ENTERTAINMENT'. The poster also mentions 'new Friends', 'GOOD FOOD', and is 'SPONSORED BY: UPSTATE'.

**WEEKEND RETREAT**

Come join us for a fun-filled weekend retreat created with stroke survivors and caregivers in mind.

**SAVE THE DATE**

**August 4-6, 2023**

**Syracuse, NY Area Stroke Camp**

**LeTourneau Christian Camp**  
Rushville, NY

SCAN THE QR CODE BELOW TO GET REGISTERED

**REGISTRATION**

Cost is \$150 (all inclusive)

CRAFTS  
EDUCATION  
PAMPERING  
DISCUSSIONS  
GAMES  
ENTERTAINMENT  
+ & MUCH MORE +

**new Friends**  
**GOOD FOOD**

SPONSORED BY:  
**UPSTATE**

Syracuse or Central or WNY  
Open to ANY survivors/care givers  
Life Changing  
Wonderful program on Canandaigua Lake  
Scholarships available  
Max of 20 survivor/caregiver pairs  
We want to fill it!

# summary



Empowering stroke survivors and their families with resources to **recover, reclaim,** and **rebuild** their lives.

- Long Beach, CA Stroke Support Association 😊



A DONE  
SOMETHING  
IS BETTER THAN  
A PERFECT  
NOTHING

“ Never believe that a few caring people can’t change the world for, indeed, that’s all who ever have. “ - Margaret Mead

# References

<https://www.stroke.org/en/help-and-support> AHA ASA resources

<https://www.stroke.org/en/help-and-support/support-group-leader-resources>

Abstract: Perceived Benefits of Peer Support groups for stroke survivors and caregivers in Rural North Carolina  
://www.ncbi.nlm.nih.gov/pmc/articles/PMC6730634/

<https://www.mayoclinic.org/healthy-lifestyle/stress-management/in-depth/support-groups/art-20044655> Support groups:  
make connections and get help

[https://en.wikipedia.org/wiki/Support\\_group](https://en.wikipedia.org/wiki/Support_group)