

Stroke Peer Support and Resources for Support Groups

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SUNY BUFFALO STATE

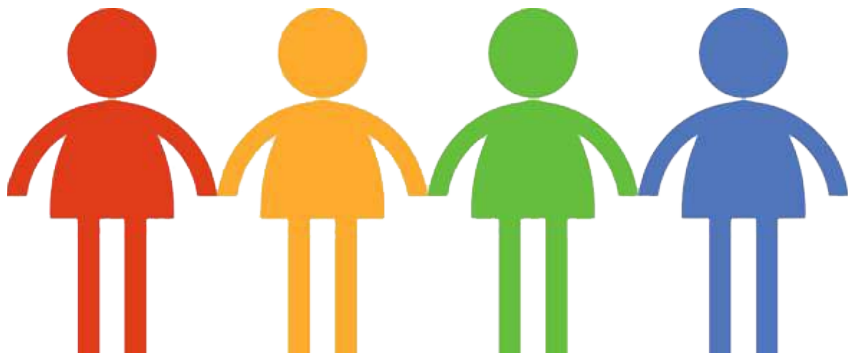
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Disclosures

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Colleagues in this endeavor



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What is a Peer Visitor?

CVA survivor

Family member of CVA survivor

Visits recent survivors in hospitals or at home

Provides encouragement & resource materials



Perceived Value of Peer Visitor to Recent Survivor

(Droegemueller, 2014; Kessler et al., 2014; Morris & Morris, 2012; Stewart et al., 1998)

Affirmation - Identify with those who have similar experience

Motivation - Hear positive survival stories

Emotional - Receive genuine support and encouragement from peer

Receive information

- In our program - packets for later reference

Hospital receives benefits

JCAHO – peer visiting program was “jewel in the crown” for Millard Fillmore Gates in Buffalo

“I love it when stroke volunteers are here” (Droegemueller, 2014)



Value to Peer Visitor

(Kessler et al., 2014)

Purpose

- Build self-esteem and self-worth
- Pride in helping others

Social connection and independence - New social role in community

Personal growth

- Learn more about stroke
- Learn new helping communication skills

Tell “their story” – our experience

Types of Peer Programs

Experienced stroke survivors and caregivers visit **new, recovering** survivors and families 1:1 (ShareGivers™; Stewart et al., 1998)

New, recovering survivors support each other in **group inpatient** settings (Morris & Morris, 2012; Muller et al., 2014)

On-going peer support groups whose members come and go (Rotherham et al, 2015; Tregea & Brown, 2013; ASA Support Network)

- On-line, phone, or face-to-face

How much training do peers receive?

Type of Program	Trainers	Time
Experienced to New (Kessler et al.; Morris & Morris; ShareGivers; Stewart et al.)	Medical and allied health	1 day, 3 -24 hours; sometimes 1-6 shadow sessions; on-going support and education
New to New (Muller et al.)	Allied health present and available	None
On-going (Rotherham et al., 2015; Tregea & Brown, 2013)	Access to allied health is a boon	None

Do we know when to visit recovering stroke survivors?

No



Each has reported benefits for peers and newly recovering but no comparisons

Should we see people in groups or One-to-One?

GROUPS

Unhelpful group members
(Morris & Morris)

People doing better or poorer than you – mixed feelings

Who chooses the conversation topics?

Recruitment (Tregea & Brown)

ONE-TO-ONE

In acute care - Are peers too optimistic? (Kessler et al.)

Telephone follow-ups are hard to complete

Better visit if peers well-matched to new, but how to do that? (Stewart et al.)

Recruitment (Insalaco et al.)

We need both one-to-one and groups

GROUPS

Support our peer visitors

Provide support for persons in chronic stage

ONE-TO-ONE

The personal touch when people need it

Peer Visitor Programs One-to-One in the hospital

ASA's Stroke Connections Peer Visitor Program d/c'ed by 2003

- Community volunteer trainers
- Administered by ASA staff
- 12, 2-hour sessions of training

ASA's ShareGivers™ Peer Visitor Program – started about 2009

- Hospital staff take over training and administration
- 14, 2-hour sessions of training

Stroke Recovery Canada® 2009

<http://thestrokethrivers.blogspot.com/2012/10/peers-fostering-hope.html>

ShareGivers™ Training Program

Hospital-based – Turnkey program

Content

- 12-16 hours of stroke education
- 8-10 hours of training in being a visitor

Peer visitors must be 18 mos. post-stroke

[http://www.strokeassociation.org/STROKEORG/LifeAfterStroke/FindingSupportYouAreNotAlone/FindaSupportGroup/Sharegivers-Peer-Visitor-Program UCM 310725 Article.jsp](http://www.strokeassociation.org/STROKEORG/LifeAfterStroke/FindingSupportYouAreNotAlone/FindaSupportGroup/Sharegivers-Peer-Visitor-Program_UCM_310725_Article.jsp)

ShareGivers™ Core Team (Bakas & Rueth, 2009)

Team Leader (usually healthcare professional)

- Enrolls key stakeholders in vision, goals, and objectives
- Facilitates acceptance of the program in the community
- Enrolls Education Coordinator and Site Supervisor(s)
- May serve as Team Leader and Education Coordinator
- Chairs team meetings

Education Coordinator (has access to healthcare professionals)

- Implements and sustains program
- Conducts screening, selection, and training of peer visitors
- Logistics coordinator, counselor, mentor, motivator

Site Supervisor (usually healthcare professional or staff)

- Coordinates visiting services at facility after training program
- Monitors and evaluates visits over time
- Provides counseling support to visitors, survivors, and families

Stroke Recovery Canada[®]/Peers Fostering Hope

Cooperation between March of Dimes and hospital

Peer screening process

- Demonstrate competencies, abilities and be of suitable character required to undertake hospital visits.
- Ability to undertake all peer support activities in a **confidential and respectful** manner.
- An understanding of, and the need to at all times, **avoid imposing religious and/or political beliefs on others**
- Ability/commitment to provide peer support for a **minimum of 1 year**

Stroke Recovery Canada® - Stroke and communication education for peers

Attend classes

Graduate with certificate

Receive shadowing and feedback

Receive on-going education

Compliance with hospital volunteer policies

Orientation

Screening

Police check

Medical examination as required by hospital
administration

Hospital Peer Visitors are considered volunteers of
both the Hospital Auxiliary and Stroke
Recovery Canada

WNY/CNY ShareGivers Program

Heavily based on Peer Visitors Program

Primary mover and coordinator is our ASA Quality Improvement staff member

- team leader
- education coordinator
- assists site coordinators – the hospital's stroke coordinator and volunteer office administrator

Trainers – allied health and medical personnel peer volunteers organized in teams

ASA and Trainers Recruit Candidates

Empathy

Good listener

Nonjudgmental

Friendly

Positive attitude

**Adequate communication –
aphasia is ok with a partner**

Willingness to share

Willingness to learn

Time availability

Transportation

Emotionally stable

Who is not a candidate?

Cognitively impaired – may not be good visitors

- poor judgment
- talk too much
- poor choice of topics/words, etc.
- poor “negotiators of the hot lava”

Poor auditory comprehension

These individuals can be encouraged to participate in other ways

Why Western New York Needs Peer Visitors

County	Cardiovascular Disease in %
Cattaraugus	12.4
Niagara	11.6
Genesee	9.8
Orleans	9.1
Erie	8.2
NYS	7.7
Monroe	5.9

WNY's process since 2003

Administrative

- Need for consistent leader at ASA who receives time and materials support from ED
- From 3 hospitals in the Buffalo area in 2004 to 4 hospitals there and 4 in Rochester
- Recognized need for periodic support for visitors
- biannual/triennial recruitment and training

Content changes

- Fewer sessions
- Need to tune into adult learning styles

Donations – Golf tournament

Initiation of Buffalo Peer Visitor Program – Fall, 2003

Caregiver sought help from American Heart and Stroke Association (ASA)

Realized need for support

Consortium formed of ASA and 3 aphasiologists from SUNY Buffalo State and University at Buffalo

ASA got it started – Contacts with Local Hospitals

ASA then Health Initiatives Director contacted local neurologists, administrators of 2 hospitals, directors of nursing and volunteer programs

3 hospitals agreed to implement

Hospitals had volunteer training and medical clearance requirements that all peer visitors had to meet

When starting a program – Need candidates

RECRUITMENT - ASA

Flyers

Local advertisers

Word of mouth and support groups

Try to enlist major media

Ideally 20 potential peer visitors per class

SCREENING INTERVIEW

Open-ended questions about history of volunteering and motivation

Gain informal knowledge of

- speech and language
- temperament
- outgoing personality
- emotional stability
- physical skills

Also

independence/transportation

Our peer training has evolved over time

From 12–two hour programs to 5 two-hour programs

Trainers – partners with local colleges' and universities' aphasiology faculty

- University at Buffalo
- Buffalo State
- Nazareth College

If we can, we add

- OT, PT, MSW
- MD, RN
- Rehabilitation counselor + neuropsychologist

Over time we realized that content and presentation method needed modifications

Typical lecture – did not engage audience

Need more role playing and active discussion

- **Especially of cultural, linguistic, gender diversity**

More carryover from class to class

More opportunity to reinforce class participants

More opportunities to voice their apprehensions

Removed sexual intimacy and finances – we recommend referral to OT and social work

Our 6th version: 5 two-hour sessions

Session	Topic
1	Introduction to Peer Visiting
	Stroke and its Effects
2	Disability and Rehabilitation
	Emotional Aspects, Well-Being, Taking Care of Yourself
3	Communication Skills, including importance of sensitivity to culture, language, race/ethnicity, gender identification
4	Making the Visit
5	Challenges in Visiting, Wrap-Up

Other Changes

Get medical clearance early

Participate in hospital volunteer training programs simultaneously

Record lessons for those who need to make up a session or do one big make-up session

Use aphasiology faculty as primary lecturers - more carryover from one lesson to another

Bring in experienced peer visitors who add credibility and spark conversation

After candidates graduate

Complete an exit interview, if needed

- some candidates know that this is not for them
- others require further explication
- others will be counseled to help in other ways

Need to celebrate

complete the hospital volunteer training and medical clearance

What has remained constant – Initial Visits

Monitored by aphasiology faculty

Paired visitors

- Preferably a caregiver and survivor
- Or 2 survivors, one must have good communication skills

Visitors provide emotional support, personal story, and information

Resource information given

Quality Assurance re: Visits

Entrance interview

Exit interviews

Monitor first visits

Keep in close touch with nursing
and hospitals' stroke
coordinators and volunteer
coordinator



Periodic Team Meetings

Meet quarterly to discuss issues

Chance for feedback from peer visitors

Identify problems and form solutions

Occasional visits to the meetings from nursing & administrative personnel



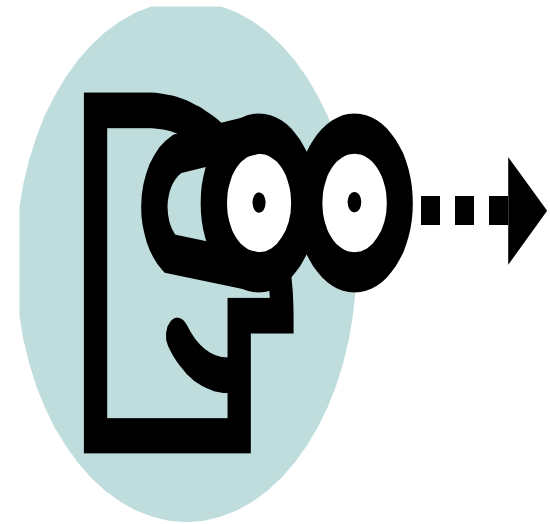
What do Peer Visitors Think of the Program?

Visits brought me closer to my spouse (CVA survivor).

Wish we had received these visits.

This is a natural extension of the family support group

But sometimes visitors do not see “fruits of their labor”



Future of the Program

Totally volunteer?

Need funding- grant to support faculty and materials on long term basis

Need to move training program around the geographical region

Need to attract visitors with diverse backgrounds



Future research – I agree with Kessler et al.

What is the preferred format and timing of visits?

Which type of stroke survivors are the most likely to benefit?



SUPPORT NETWORK

What are the objectives of the Support Network?



The Support Network establishes AHA/ASA as a trusted source for patients, families and caregivers.

- **Facilitates** emotional connections to deepen engagement between AHA/ASA and patients, caregivers and volunteers
- **Creates** meaningful volunteer roles virtually and in their own cities and neighborhoods
- **Improves** knowledge, healthy behaviors and quality of life



What is the Support Network?

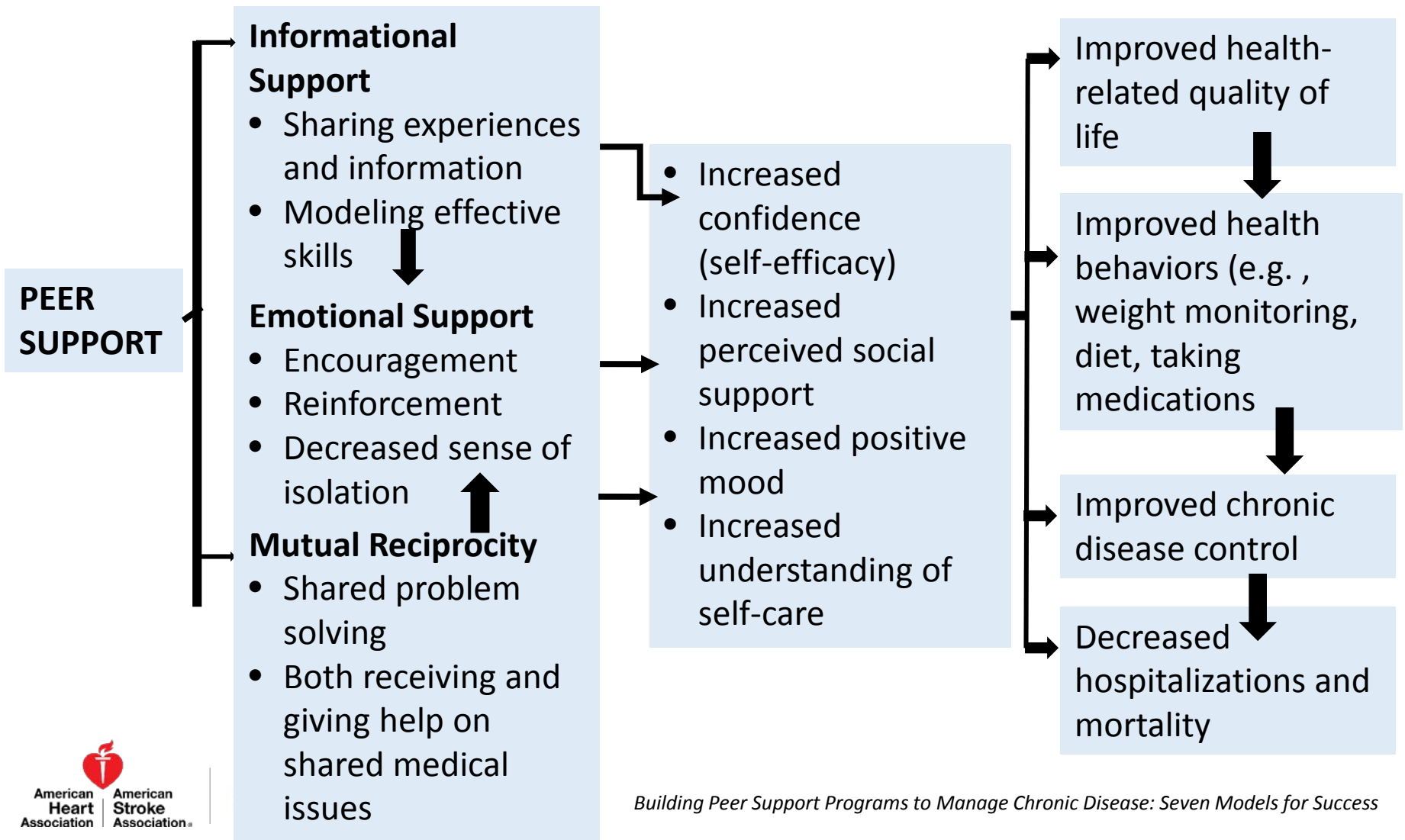


Our support platform is dedicated to serving those who have experienced stroke or heart disease and their caregivers.

It is designed for individuals, their families and caregivers to meet others, share their stories, and to find and give support.



How Peer Support Can Improve Chronic Disease Outcomes





How does the support make a difference?

Patients achieve a higher quality of life:

- Reduced sense of isolation
- Peer-to-peer connection
- Support and encouragement for improvement

Family supporters experience:

- Less burnout
- More attention to self care
- Sense of encouragement and confidence
- Shared resources
- Sense of support

Hospitals, rehab centers and healthcare providers benefit by:

- Reduced patient anxiety and lessened emotional burden
- Increased focus on pursuing solutions for problems
- Lower readmission rates
- Enhanced clinician – patient communication

• Citations are available on the impact of support





What are the benefits of the Support Network?

- When your patients join the Support Network, they join a community of people who have been where they are and understand the complications a heart or stroke diagnosis can add to your life. But it's not just about getting support, there are benefits to providing support, too. By providing support, you enhance a person's feeling of being cared for
- Sense of available, reliable help
- Opportunities for empathy and warmth
- Education and resources for coping with change
- Your patients will also feel better and more in control of their own life, which can mean a lot during hard times.
- You are providing them with resources for when they leave your care!





How do I connect to the Support Network?

www.strokeassociation.org/supportnetwork

Once registered, users are directed to their home page to build a profile:

- Basic Info
- Reason for Joining
- Personal Info about your Stroke

The screenshot shows the user interface of the Support Network. At the top left is the American Heart Association logo with the tagline "life is why". To the right are social media icons for Facebook, Twitter, YouTube, and Google+, followed by a "MY ACCOUNT | LOG OUT" link. Below this is a search bar. A dark navigation bar contains links for HOME, HEART, STROKE, CHRONIC CONDITIONS, COMMUNITIES, RESOURCES, VOLUNTEER, and BLOG. Below the navigation bar, a row of links includes MY ACCOUNT (highlighted in red), MY CONTENT, EDIT PROFILE, INVITE, and VIEW PROFILE. The main content area is divided into three columns: 1. "CUSTOMIZE SETTINGS" with a sub-section for "Account" and text: "Here you can update the name other members see on your profile, and change your account email and password." 2. "MY ACCOUNT" with sub-sections for "Account", "Privacy", "Notification", and "Subscriptions", and a "My Account" heading with "Contact Information" below it. 3. "HOW TO SUBSCRIBE" with text: "Would you like to be notified of updates to particular conversation categories or topics? Just hit the 'Subscribe' link above that content, select your frequency, and you'll receive email updates of new posts."



Connect your patients to others like them!

- Stroke
- Pediatric Stroke
- Cryptogenic
- Ischemic
- Hemorrhagic
- Transient Ischemic Attack
- Caregiver
- Rehab and Recovery

MY ACCOUNT | LOG OUT

American Heart Association | American Stroke Association. life is why.

SUPPORT NETWORK

HOME | HEART | STROKE | CHRONIC CONDITIONS | COMMUNITIES | RESOURCES | VOLUNTEER | BLOG

LIFE AFTER A STROKE.
What are the changes you need to make after a stroke? Learn from people just like you.

Stroke

RECENT CONVERSATIONS | SEARCH THIS CONVERSATION



Find a Support Group



**I want to start
a support
group ...**



1. **Download our Leader Training Materials & Meeting Guides**
2. **Register your group**
3. **Get connected to the Leader Resource Center**
 - Local staffer reaches out to thank them and connect to other relevant local opportunities



**I want to
connect my
support group
to AHA/ASA ...**



1. **Download our Leader Training Materials & Meeting Guides**
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 - Local staffer reaches out to thank them and connect to other relevant local opportunities



**I want to join a
support group ...**



1. **Find a virtual support group or enter your zip code to find one near you**
 - Local staffer reaches out to thank them and connect to other relevant local opportunities



How you can help as a Healthcare Professional ?

- Connect patients and family to the Support Network while in the hospital
- Walk Stroke Coordinators through site registration
- Download the AHA/ASA promotional materials from www.strokeassociation.org/Supportnetwork
- Register on the Support Network & experience it for yourself
- Join Conversations



“On AUG. 26, 2014 I had a stroke. (CVA) Nothing has been the same. It's like my whole world has been turned upside down. After 4 months I still have a lot of weakness on my left side. I'm in a foot brace and walk with a cane. I'm dealing with anger, anxiety, depression, comprehending, expressions and much more. I'm unable to return to work. I find it hard to motivate myself to wanting to do stuff. I'm wondering if thing will get better after a stroke...”

Anonymous Stroke User's initial post- conversation has sparked more than 16 posts from multiple users



Questions?

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