Building a Stroke Support Group

Dianne Price, RN Kingwood Medical Center Stroke Coordinator
Learning Objectives

• **Why** Start a Stroke Support Group?
• **How** To Start a Stroke Support Group?
• **Who** Should Attend?
• **When** Should We Meet?
• **Where** Should We meet?
• **What** Happens?
• Lessons learned
Why Start a Stroke Support Group?

• Stroke = life-altering experience for both the victim and the family

• Support groups are a great way to meet other stroke survivors and caregivers who understand what you are going through.

• Participants can learn and share practical experiences and resources.
Why?

According to stroke survivors:

- Stroke affects everyone differently
- Attitude determines everything
- “New Normal”
- “I don’t know when I need to ask for help”
- Fear of unknown
- There IS “Life After Stroke”
- Role changes/reversal...
- Come to find support “when you’re ready”
Why?

According to Caregivers:

• Don’t have to feel so alone

• Get encouragement, practical tips and wisdom for recovery

• May be a “safe place” to share fears, frustrations and ask for help or support

• Role changes

• Place to get resources, help and understanding
Why?

According to Healthcare Providers:

• Learn what is going on for patients and caregivers after discharge
• Offer support, knowledge, professional experience and resources
• Maintain supportive connection to patients and families after discharge
• Learn practical tips and community resources from survivors and caregivers to share with others
• Can reshape what and how patient education resources are available and provided.

• REWARDING to see survivors & families improve
How To Start a Stroke Support Group?

• Find out if other support groups are offered at your hospital or in your local area
  • Has there ever been a stroke support group?
  • Meet with facilitators of other groups
  • Find out their meeting place/times to prevent conflicting schedules
How?

• Identify Leaders/Facilitators (2-5 if possible and available)
  • Strengths/Weaknesses
  • Inpatient and Outpatient
  • Multidisciplinary Team
  • Always have a back-up plan in case!!!
How? Facilitator Relief

• Get 1-2 additional facilitators in beginning if possible
• Rotate to allow different perspective
• Allows for time off or vacation for facilitator
• Back up/support for each meeting
How?

• Ask about funding
  • Snacks
  • Marketing (flyers, mailings, advertisements)
  • Speakers, facilitators

• Ask about support
  • Administrator to help with registration and answering questions
  • Marketing
  • Meeting rooms
  • Outlook Distribution group email contact
How?

- Contact stroke survivors
  - Education packets at discharge
  - Flyers at clinics (follow-up appointments)
  - Stroke Seminars
  - Community centers
  - Website (Nat. Stroke. Assoc. directory)
  - Collect email and start distribution list (use BCC)
How?

- [http://www.strokeassociation.org/STROKE](http://www.strokeassociation.org/STROKE)

**Stroke Support Groups**

Find a Stroke Support Group in Your Area
Use our Stroke Group Finder by entering your ZIP code and a mileage radius to find registered stroke groups near you.

Register Your Group
Do you lead, or know of, a group in your area that isn't listed in our registry? Download our Stroke Group Registration Form (PDF) and get listed today!

Successful Stroke Support Groups
Download this comprehensive 30-page booklet that guides you through starting and maintaining a viable stroke support group.

Online Support
No support group in your area, or do mobility or time restrictions make it hard to make it to a group? You can attend these groups on your schedule, without leaving the comfort of home.
Welcome to our national stroke support group registry. To find a group near you, simply enter your ZIP code and a mile radius. If your initial search does not pull up any groups, try increasing your mile radius.

Once a group, or list of groups appear, you may click on any group for more details about them.

If you’re a group leader and would like to update your information or register your group, visit our Support Group Leaders section.
How?

- [www.stroke.org/supportgroups](http://www.stroke.org/supportgroups)
Examples of Website
You are invited to our Aneurysm & Stroke Support group  STARS
Meeting Dates: Monday evenings

Jan 19th, 2015
March 16th, 2015
May 18th, 2015
July 20th, 2015
Sept 21st, 2015
Nov 16th, 2015

Time: 6-7 pm
FREE Dinner will be served

Location: Kingwood Medical Center Community Room
Parking: Entrance C (West entrance of the Hospital)
For more information call:
281-348-8975 or to RSVP dinner reservation
Email dianne.price@hcahealthcare.com
Hi! It's that time again!

We are looking forward to seeing you all TOMORROW (August 3) for the next Stroke Support Group.

We will meet in a NEW room. If we all like this location this will be our new "permanent" spot! Please join us from 2:30 - 4 in room AIP 1010. This room is located on the 1st floor down the hallway that connects the inpatient and outpatient buildings. The room is on the INPATIENT side but easily accessible through either entrance. Look for signs tomorrow. Also, Bill and Alex will be roaming the halls to point you in the right direction!

We will be discussing communication skills to follow up on last month's presentation by Lisa, a speech therapist. Come join the discussion about assertiveness, techniques to practice in social conversations, questions to ask your doctor, and MORE!

We are looking forward to seeing you.
Thanks, Wendy, Bill and Alex
Example of a Email Reminder

Happy New Year STARS
REMINDER... Monday January 19th at 6 pm is our first 2015 STARS support group meeting here at Kingwood Medical Center in the community room
Please RSVP by responding to this email or call the STARS line and leave a voice mail
See you Monday  dianne

Dianne Price RN  **Stroke Program Coordinator**
Kingwood Medical Center Hospital l an HCA affiliated Hospital
**STARS line**  281 348-8975  Fax 281 348-8055

[Website Link](http://www.kingwoodMedical.com)
Who Should Attend?

- Stroke Survivors
- Caregivers
- All Ages
- All Abilities/Disabilities (TIA)
- Time from stroke

- Guests
  - Students
  - Family members
  - Other healthcare providers
When Should We Meet?

- Frequency
- Day of week
- Time of day
- Duration
- Same time and day of week

- Other Considerations:
  - Traffic, parking, security, volunteers at information desk
  - Driving in the dark
  - Room availability
  - Food services support...feed them... they will come!!!
  - What’s convenient for your leadership team?
Where Should We Meet?

• Near restrooms
• Wheelchair accessible
• Easy parking access
• Same room in an easy to find location
Where Should We Meet?

- Adequate space for number of people to feel comfortable
  - Location may change if group outgrows current space
- Roundtable or face to face
- Refreshments
What Happens at Support Groups?

• Involve members in planning
• Stay flexible
• Keep purpose statement in mind
• Can have different discussions for survivors and caregivers
What Happens at Support Groups?

- Consistent format
  - Welcome
  - Introductions
  - Announcements
  - CONTENT
  - Closing
What Happens at Support Groups?

• Content
  – Formal presentation by facilitator, guest or member
  – Group sharing and discussion
  – Topic of the month
  – Activity (group/individual)
  – Book review
What Happens at Support Groups?

- Special activities
  - Dining out
  - Holiday events
  - National Stroke Awareness Month
  - Birthdays
  - Field trip
  - Volunteer opportunity
What Happens at Support Groups?

- **iHOPE** webinars ([www.stroke.org/ihope](http://www.stroke.org/ihope))
- Stroke advocacy network
What Happens at Support Groups?

• First Meeting (organized and purposeful)
  • Welcome
  • Introductions
  • Goals
  • Purpose Statement
  • Ground Rules
  • Ideas for future scheduling

• Importance of the group feeling OWNERSHIP, not the facilitators!
Example of Purpose Statement

• We are an educational support group for stroke survivor’s and their caregivers that seeks to provide evidence based information, mutual support, structure, and resources that promote increased independence and quality of life.
Example of Ground Rules

1. Confidentiality is essential. We expect that each person will respect and maintain the confidentiality of the group.
2. We try to give everyone an opportunity to share their thoughts, feelings, and experiences.
3. We give supportive attention to the person who is speaking.
4. Each of us is encouraged to participate to whatever extent we feel comfortable.
5. Personal information never shared
6. Never barrage group with email or calls
7. We begin and end our meetings on time.
Needs of Group

- New members – anxious
- Need to share experiences and ask questions
- Willingness of group members to reach out to each other, as well as needed resources
Lessons Learned

People Pitfalls
- Shopper
- Dominator
- Businessman
- Over-the-top happy
- Down in the dumps
- Disagreements
  - Survivor-to-survivor
  - Survivor-to-caregiver
Lessons Learned

• Share options – learn from others
• Try new ways – avoids becoming routine
• Brainstorming
• Ask your group!
  • What did you like about the last meeting?
  • What has been most helpful?
  • What would you change?
  • Is there enough time for visiting and sharing?
Thank you for your time!
dianne.price@hcahealthcare.com