ShareGivers Program
Overview

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What is ShareGivers?

- Peer visitor program for stroke survivors and their families.
- Peer visitors are stroke survivors and caregivers who have completed the ShareGivers training course.
- Peer visits are made to newly diagnosed stroke survivors and their family caregivers at hospitals, rehabilitation centers, nursing homes, and other inpatient facilities.
- Developed by the American Stroke Association
Background

- Stroke is the 3\textsuperscript{rd} leading cause of death in the United States. (Lloyd et al., 2009)

- Each year, 795,000 people experience a stroke. (Lloyd et al., 2009)
  - 610,000 are first attacks
  - 185,000 are recurrent attacks (23%)
Background

- Prevention of a second stroke through risk factor management is critical. (Sacco et al., 2006).
  - Hypertension
  - Atrial Fibrillation and other cardiac conditions
  - Diabetes
  - High Lipids (Cholesterol and Triglycerides)
  - Cigarette smoking
  - Heavy alcohol consumption
  - Obesity
  - Lack of physical activity

- Management of these risk factors often require complex and difficult: (Sacco et al., 2006).
  - Lifestyle modifications (including exercise)
  - Dietary guidelines
  - Medication regimes
**Background**

- **Stroke is a leading cause of severe, long-term disability.** (Lloyd et al., 2009)

- **Among ischemic stroke survivors ≥ 65 years of age, at 6 months after stroke:** (Lloyd et al., 2009)
  - 50% had some hemiparesis
  - 30% unable to walk without assistance
  - 26% were dependent in ADL
  - 19% had aphasia
  - 35% had depressive symptoms
  - 26% were institutionalized in a nursing home

- These stroke-related impairments and consequences make it very difficult for survivors to reintegrate back into the community.
Background

- Approximately 68% to 74% of all stroke survivors require care in the home by family members. (Dewey et al., 2001; Dorsey & Vaca, 1998).

- Caregiver stress is a leading cause of costly long-term institutionalization of stroke survivors (Han & Haley, 1999).

- Lack of appropriate discharge planning along with early discharge of stroke survivors can place unrealistic demands on caregivers. (Anderson et al., 2000; Ski & O’Connell, 2007).
Background

- **Stroke Caregiver Needs and Concerns** (Bakas et al, 2002).
  - Finding information about stroke
  - Managing the survivor’s emotions and behaviors
  - Providing physical care
  - Providing Instrumental care
  - Dealing with one’s own personal responses to providing care
    - Caregiver emotions
    - New responsibilities
    - Asking family and friends for help
    - Keeping own social life going
    - Taking care of one’s own health
Background

- **ASA Recommendations for the Establishment of Stroke Systems of Care.** (Schwamm et al., 2005).

  - A stroke system should support educational programs that target high-risk populations (such as those with previous stroke) and their families.

  - A stroke system should ensure that stroke patients and their families receive education about stroke risk factors and warning signs.

  - A stroke system should establish support systems to ensure that patients discharged from hospitals and other facilities to their homes have appropriate follow-up.

    - Includes education and training for the patient and his or her family members.
Background

- AHA/ASA Endorsed Practice Guidelines: Management of Adult Stroke Rehabilitation Care. (Duncan et al., 2005).
  - Patient and family education improves informed decision-making, social adjustment, and maintenance of rehabilitation gains.
  - Recommend that providers be alert to the stress on the family/caregiver, … and providing support, as indicated.
  - Recommend that patients and families be given information, advice, and the opportunity to talk about the impact of the illness on their lives.
Purpose of the ShareGivers Program

- To educate stroke survivors and their families about stroke
- To provide hope and encouragement to stroke survivors and their families
- To make a difference in people’s lives
- To promote collaboration between the American Stroke Association and community partners (e.g. hospitals) to help stroke survivors and their families live with stroke.
Purpose of the ShareGivers Program

- Does not interfere with stroke treatment by healthcare providers
- Supplement to enhance the professional care of stroke survivors and their families.
- Accessible as a kit – and also available online.
  - Call the Warmline 1-888-4-STROKE (478-7653)
  - Visit StrokeAssociation.org/ShareGivers to register.
ShareGivers Program Models

- Community-based model
  - Involves 2 or more health care facilities
  - Each facility has a site coordinator

- Self-contained model
  - Launched by a single facility
ShareGivers Core Team

❖ **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** (access to healthcare professionals)
  - Implementing and sustaining 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
  - Monitoring and evaluating visits over time
  - Provides counseling support to visitors, survivors, and families
Timeline

6-10 months prior to training
- Convene initial meeting of Core Team
- Assess community readiness and feasibility
- Establish goals and objectives
- Establish training course dates and general logistics
- Assess needs, costs, gaps, & sponsorships
- Contact local ASA for advice

4-8 months prior to training
- Promotional activities to recruit peer visitor candidates
- Planning and preparation for training
Timeline

- 2-4 months prior to training
  - Visitor recruitment, screening and selection process
  - Establish policies and processes for on-site visits

- As training conducted
  - Promote availability of ShareGivers program

- 1-3 months after completion of training
  - Overall program evaluation
Peer Visitors

- Peer visitors can be:
  - Stroke survivor
  - Family caregiver or someone who has lived with a stroke survivor
  - Healthy and able to participate in the 12-week program and able to make visits after training
  - At least 18 months post-stroke
  - Have a mature attitude toward their own stroke
  - Committed to helping stroke families address emotional and social concerns
  - Supporters of conventional stroke rehabilitation programs
  - Personal integrity with a track record of respecting confidentiality
Class structure

- Lessons 1-8 (Education sessions) meet weekly for 1 ½ to 2 hours
  - Class size of 12-16 stroke survivors and their family members (typically 1 per survivor)

- Lessons 9-12 (Peer visitor training) meet weekly for 2 to 2 ½ hours
  - Class size of 12 or less peer visitor candidates (stroke survivors and family members who wish to become peer visitors).

- Graduation ceremony
Lesson 1

- Exploring the Facts and Figures of Stroke
  - Overview of ShareGivers training course
  - Build knowledge base about causes, etiology, and treatment of strokes
  - Includes risk factors and warning signs for stroke
    - Sudden weakness or numbness of the face, arm, or leg
    - Sudden confusion, trouble speaking, or understanding
    - Sudden trouble seeing in one or both eyes
    - Sudden trouble walking, dizziness, loss of balance
    - Sudden severe headaches with no known cause
Lesson 2

- Exploring the Benefits of a Rehabilitation Team
  - Rehabilitation as an ongoing process
  - Define own rehabilitation plan
  - Communicating needs to appropriate healthcare professionals
  - Dealing with aphasia
Lesson 3

- Exploring the How and Why of Living with a Disability
  - Health challenges of living with stroke
  - Self-care strategies for managing these challenges
    - Short-term memory loss, problem solving
    - Behavior and fatigue
    - Medication management
    - Nutritional management
    - Managing high blood pressure
Lesson 4

- Exploring the Emotional Aspects of Well-Being
  - How stroke affects emotions
  - Healthy ways to express feelings to others
  - Stress management strategies and positive self-talk
Lesson 5

- Exploring the Meaning of Self-Esteem and Intimacy
  - How stroke creates changes in:
    - Body image
    - Self-esteem
    - Roles and relationships
    - Sexual intimacy
  - Find ways to affirm positive changes
Lesson 6

• Exploring Creative Ways to Encourage a Positive Lifestyle

• Ways of maintaining health while living with disabilities
  • Proper nutrition
  • Exercise to the best of one’s ability
  • Monitor blood pressure
  • Intellectual learning and new ideas
  • Social activities
  • Emotional well-being
  • Spiritual well-being (meaning and purpose in life, faith)
Lesson 7

- Exploring Financial Wellness
  - Finding resources in the community
  - Ways of managing finances
    - Personal savings
    - Disability benefits, etc.
    - Legal issues, living wills, etc.
  - Possibility of returning to work
  - Living arrangements
Lesson 8

- Exploring Emotional Wellness and Living in the Present
  - Characteristics of a thriving survivor
  - Value of living in the present
  - Community resources
Education Certificate

This Certificate of Recognition
Is hereby granted to

__________________________

On this day

__________________________

For successfully completing the stroke educator course requirements for ShareGivers, a peer visitor program.
Lesson 9

- Introduction to Peer Visiting
  - Rationale behind peer visiting
  - Peer visitor guidelines
- Active Listening Skills I
  - Encourage person to share
  - Show you are interested and understand
  - Learn caution before giving advice
  - Stay focused on person’s story and feelings
  - Respect for family’s values and feelings
- Role Playing
Lesson 10

- Visitor-Client Relationships
  - Identify unique qualities of peer visitor
  - How to meet and greet new stroke families
- Active Listening Skills II
  - Show you Understand (rephrase what you hear)
  - Ask open ended questions
- Role Playing
Lesson 11

- Handling Difficult Situations as a Visitor
  - Identify challenging situations
  - How to handle challenging situations
  - How and when to make referrals
  - How to recognize depression and suicide potential
  - Active Listening and Role Playing
Lesson 12

- Exploring the Visitor-Supervisor Relationship
  - Clarify relationships among
    - Peer visitors
    - ShareGivers Site Supervisors
    - Cosponsoring agencies
  - Active Listening and Role Playing
Diploma of Graduation

This Diploma of Graduation
Is hereby granted to

____________________________________

On this day

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For successfully completing the course requirements for becoming an active visitor for ShareGivers, a peer visitor program.
Resources in the Sharegivers Kit

- Program guide
- Job descriptions for
  - Team leader
  - Education coordinator
  - Site supervisor
  - Peer visitors (along with screening questionnaire)
- Timeline
- Evaluation forms
- Certification tests
- Visit reports
- ASA fact sheets
- The 12 Lesson plans
Resources in the Sharegivers Kit

- **DVD Video Clips**
  - Gift of caring
    - Experiences of family caregivers
    - Suggestions and advice
  - Recovering after stroke
    - Experiences of stroke survivors
    - Lifestyle changes and rehabilitation
  - You’re not alone
    - Emphasizes positive attitudes and benefits of support groups
  - What is aphasia
    - Covers different types of aphasia
    - Experiences of aphasic survivors and their caregivers
- **Additional ASA resources**
  - Warmline answered by peer survivors and caregivers
  - Stroke Connection Magazine
  - Pamphlets and patient education materials
  - Online resource center
  - Access to support groups in your area
Additional Suggestions

★ Use most of the materials provided in the ShareGivers program kit.
★ Realize that every peer visit is different
★ Have new peer visitors co-visit with experienced peer visitors
★ Remember to give peer visitors feedback
References

References

Thank you!