Brain Injury Peer Support

The million small victories Institute.

UPMC Rehabilitation Institute

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Deficits After Neurological Injuries

- Physical deficits
- Non-visible deficits
  - Cognitive
    - Memory
    - Problem solving
    - Attention
    - Comprehension/expression
  - Social
    - Inappropriate social interaction
    - Tangential conversations; unrelated topics
    - Egotistical
    - Show no empathy or interest in others
    - Uncensored

Decreased stimuli
Decreased contact with the outside world
Decreased independence
Revoke license

Social Isolation

Relationships Deteriorate

- Friends begin to drift away
- Extended family disengages
- Difficulty understanding social deficits
- Decreased empathy with coping skills
- No longer have things in common

Caregiver Burden

- Caregiver for the survivor both physically and cognitively
- Requirement of 24 hour supervision
- Adapting to the change in relationship
- Feelings of guilt
- Stress and frustration
- Neglect themselves

Need for Support

- For the survivor, caregivers and family members
- A non-judgmental place to vent
- Ability to share experiences
- Socialize with others dealing with similar experiences
- Advice and resources
- New friendships
Benefits of Support Groups

- Feeling less lonely, isolated or judged
- Decrease depression and stress/anxiety
- Feel a sense of control
- Can be more open and honest about feelings
- Find others who have common ground
- Increase motivation for life
- Other members can provide honest perspective regarding behaviors/feelings

Types of Support Groups

- In person
- Internet
- Over the phone
- They can be lead by professionals or self led by participants

Format of Support Groups

- Structured
  - Educational
  - Guest speakers
- Informal
  - Open discussion
- Social activities/outings

Brain Injury Support Group

Brain Injury Statistics

- Nationwide
  - CDC estimates 5.3 million living with a disability resulted from a BI (1999)
- PA
  - 245,621 live with BI
  - 8,612 life-long or long term disabilities

Purpose of BI Support Group

- Peer support
  - BI survivors and caregivers
- Share common ground
- Emotional support
- Social interaction
- Community reintegration
Brain Injury Support Group

- 2nd Monday of every month
- 6-7:30 pm
- UPMC Mercy Hospital
- Brain injury survivors, caregivers, and family members

Let’s Talk About It

- Open discussion
  - Occasional re-direction
- Open ended questions
- Involve everyone
- Guest speakers

Support Group Topics

- Returning to work/volunteering
- Coping methods
- Anger management
- Everyday and new struggles
- Driving/Transportation
- Goals
- Achievements
- Upcoming events

Keys to a Successful BI Support Group

- TBI survivors, caregivers, family members
- Insight, insight, INSIGHT
- Transportation
- Marketing
  - Website
  - Discharge instructions
  - Doctor referrals
  - Word of mouth

Unmasking Brain Injury

- Hinds’ Feet Farm
  - Non-profit organization
  - Serve those with a brain injury

- “To promote awareness of the prevalence of brain injury; to give survivors a voice and that means to educate others of what it’s like to live with a brain injury; to show others that persons living with a disability due to their brain injury are like anyone else; deserving of dignity, respect, compassion and the opportunity to prove their value as citizens in their respective communities”

- Traveling exhibition to promote brain injury awareness
Love Your Brain

- Embodies the positive approach to brain injury prevention and healing
- Improve the lives of those affected by TBI
  - Build community
  - Foster resilience
  - Promote importance of loving your brain
- Kevin and Adam Pearce
  - “The Crash Reel”
  - Love Your Brain Yoga

Love Your Brain Yoga

- Gentle yoga
- Offered to TBI survivors and caregiver
- Low stim environment
- Incorporates strategies to focus attention and release negative thoughts
- Facilitated TBI-related group discussions
  - Foster resilience and compassion

Requirements of LYB Yoga

- Able to move without assistance
- Ability to follow instructions
- Regulate intense emotions
- Commitment to all 6 classes
- Younger than 70 years old

Additional Brain Injury Support Groups

- Allegheny County
  - Carnegie Brain Injury Support Group
    - Carnegie Borough/Municipal Bldg
    - Contacts: Sarah Fischer (877)-480-6714 x140
    - Darey Peer (877)-480-6714 x129
    - 1-3 pm November 29
  - Moving Ahead Support Group
    - HealthSouth Harmarville Rehab
    - Tom Byrnes (412)-670 4861
    - Susan Little (412)-828-1300 x7248
    - 7-9 pm 2nd Tuesday of the month
Additional Brain Injury Support Groups

- Allegheny County
  - Shadyside Brain Injury Support Group
  - Remed
  - Contact: Monica Belawski (412)-956-1694
  - 7-9 pm 3rd Monday of the month

- Butler County
  - Mind Matter: The Butler Support Group
  - Butler Memorial Hospital
  - Contact: Dottie Ardel (724)-283-6666
  - 7-9 pm 3rd Monday of the month

Stroke Support Group
True Life After Stroke

Stroke Awareness
Michigan Survey 2,500 Adults

What percentage of people surveyed could name one stroke risk factor?
80% could name at least one stroke risk factor

What percentage could name 3 risk factors?
27.9% named 3 risk factors

Stroke Awareness in Public
Michigan Survey 2,500 Adults

The most common risk factor identified was:

Answer: Hypertension 32.3%
Smoking 29.2%
Physical inactivity 25.9%
Diet 24.5%
Unable to list one risk factor 20%

Most stroke patients do not seek immediate medical attention.

What percent of patient arrive in the ED within 3 hours of symptom onset?
- Only 25% of patients arrive at the ED within 3 hours of symptoms onset
- In recent years the percentage of patients arriving within 3 hours of symptom onset has not increased
- Delays can be related to poor recognition of stroke symptoms and lack of awareness
  - Medical attention for stroke victims is time sensitive
True Life After Stroke

- Support group meetings
- 2nd Saturday each month
- Clark Auditorium at UPMC Mercy Hospital
- 10 AM – 12 PM
- Open to all stroke survivors, caregivers and family members interested

Stroke Group Facilitator

- Stroke specialized practitioners
- Stroke survivors
- Caregivers or family members
- Local organizations

Educational Presenters

- Occupational Therapy
- Physical Therapy
- Speech and Language Pathology
- Physiatrist
- Psychologist
- Pharmacist

Benefits of Stroke Support Group

Peer Support

Community Re-Integration

Socialization
Stroke Awareness in the Community

Create a Stroke Support Group
- Stroke Awareness
- Funding
- Marketing
- Location

Funding for Stroke Group
- Hospital Stroke Programs
- Rehabilitation Programs
- Drug Companies
- Grants

Marketing Stroke Group
- Advertise in hospital on stroke units
- Post flyers in Rehabilitation units and in gym
- Place flyers in stroke clinics
- Place your support group on AHA/ASA web page
- http://www.strokeassociation.org/STROKEORG/
- Place your support group on NSA web page.
  http://www.stroke.org/
- Place in stroke education material for inpatients

Stroke Group Locations
- Hospital Meeting Areas
- Church Social Halls
- School Rooms
- Senior Citizen Gatherings
- Town Social Halls
Mission:
The mission of Retreat & Refresh Stroke Camp is to improve the quality of life for stroke survivors, caregivers, and their families. This is accomplished through weekend retreats, as well as community stroke education and awareness events for the public.

"In September of 2001 my husband, John, suffered a stroke at the age of 55, an event that changed our lives forever... My family has had a lifelong love of camping, so planning and executing the camp wasn’t particularly frightening. With the help and support of countless individuals, we were able to realize our dream."

Marylee Nunley
Executive Director

The first camp was held in September of 2004 in IL and is now grown to include non-profit status and a national network of stroke camps for stroke survivors, caregivers, and family members.

5 board members, 15 volunteers
20 Survivors, 20 caregivers

We received a grant to host Retreat & Refresh Stroke Camp in the Pittsburgh area for June 2016 and 2017. Our goal is to make camp an annual event.

Some people want it to happen, some wish it would happen, others make it happen.
- Michael Jordan
What Do We Do?

- Break-out discussion groups for survivors and caregivers
- Educational sessions
- Relaxation and pampering
- Fun activities indoors
- Outdoor activities
- All activities are organized, supervised and adapted to meet the needs of every participant

Who Should Attend?

- Stroke survivors, caregivers, and their family members who can attend a three day weekend.
- If survivors will be coming alone, they need to be able to perform all activities of daily living.
- The Camp Nurse can monitor and assist with medications if needed.
How Can RRSC Help?

• Losses faced by survivors and caregivers
  – Independence, speech, driving, socialization, family/friends, future aspirations, control, companionship, confidence
  – Communication, intimacy, independence, relationship with spouse as a partner, freedom, personal time, travel, friends

How Can RRSC Help?

• Challenges faced by survivors and caregivers
  – Finances, medications, support, isolation, fear of being alone, rehabilitation, schedule conflicts

Reflections

“...As a caregiver, there is very little understanding/support for this life changing role. [Stroke camp] gave me an expanded view of the perspective and contributions of the survivors.”

  - Stephanie Alberts, Caregiver at Stroke Camp 2016

Reflections

“...My favorite part was the stroke conquerors’ connecting on a shared experience, spiritual and emotional levels. We were able to see that we are not alone in our journeys. I felt like a conqueror this weekend! We are all warriors still fighting for our survival.”

  - Audra Walker, Survivor at Stroke Camp 2016

Reflections

“...I arrived as a volunteer who was prepared to do anything that was asked of me. I left a more compassionate member of the rehab team with a renewed love and respect for my job...after my weekend at stroke camp I have realized that I could never be happy doing anything else with my life.”

  - Jocelyn Joseph, Volunteer at Stroke Camp 2016
See You at RRSC!

UPMC Rehabilitation Institute and UPMC Stroke Institute host Stroke Camp annually at Crestfield Camp and Conference Center in Slippery Rock, PA.

See You at RRSC!

$125 per person for caregivers and survivors including lodging, meals, daily activities

Online or mail registration

www.strokecamp.org

Brain Injury Resources

- Center for Disease Control
  - https://www.cdc.gov/traumaticbraininjury
- Brain Injury Association of America (BIAA)
  - http://www.biausa.org/
- Brain Injury Association of Pennsylvania (BIAPA)
  - http://www.biapa.org/
- Hinds’ Feet Farm
  - Unmasking Brain Injury
    - http://www.hindsfeetfarm.org/home.asp
- Love Your Brain
  - http://www.loveyourbrain.com/
- Brain Injury Support Group
  - https://upmc.asapconnected.com/CourseDetail.aspx?CourseId=75048
    - Olivia Houser: 412-232-4023
    - housaro@upmc.edu

Stroke Resources

- American Heart/Stroke Association
  - Strokeassociation.org/STROKEORG/community
- National Stroke Association
  - www.stroke.org
- Genentech
  - StrokeAwareness.com
- Center for Disease Control
  - CDC.gov/stroke/materials_for_patients.htm
- NINDS—know stroke campaign
  - Stroke.nih.gov/materials

Stroke Support Resources

- American Stroke Association “Stroke Family Warmline”
  - 1-888-478-7653
- True Life After Stroke Support group
  - Kathy Seiler: 412-232-8738
  - seilerkr2@upmc.edu
- Retreat and Refresh Stroke Camp
  - Strokecamp.org
    - 309-688-5450
    - Stacey Davis: 412-232-4055
    - daviss11@upmc.edu
Questions???