



BRAIN DAMAGE CASES

FROM A BRAIN INJURY SURVIVOR:
HOW YOUR CLIENTS AND THEIR FAMILY CAN
BENEFIT FROM PARTICIPATING IN A
BRAIN INJURY SUPPORT GROUP

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Decatur, Georgia

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INTRODUCTION

Thank you, Marc Davis, for inviting me to speak to the ICLE Seminar about support groups for people with brain injuries. I am always happy to help those with brain injuries and to suggest ways that those without brain injuries can help this population also.

I sustained a major brain injury in 1991, and because of my personal experiences I did found and continue to facilitate the Brain Injury Support Group of Newton/Rockdale County.

June 1991 was a rainy day, and I was returning from visiting my mother who was a stroke patient at Westbury Nursing Home in Jackson. A man hydroplaned, crossed the center line and hit me head-on. My truck was trapped against an embankment and caught fire.

Luckily, a man came across the accident, and he had the equipment and knowledge to wench my door away from the frame and pull me, unconscious, from the blazing vehicle. (The fire was so intense that his tennis shoe bottoms melted when he originally stood in the bed of the truck and tried to pull me through the back window.)

I sustained severe brain injuries - primarily to the left frontal lobe and serious damage to my left eye that required surgery.

I spent several weeks in a deep coma, 3 months in hospitals at Macon and Emory, and several months in the day rehabilitation program at the Emory Rehabilitation Center.

While I was a patient at Emory my family and I attended their support group for brain injury survivors, their families and caregivers. We also became aware of the Brain Injury Association of GA which was housed then, as it is now, at the Emory Rehabilitation Center.

BENEFITS OF SUPPORT GROUP PARTICIPATION

Support groups provide safe and encouraging venues for people with brain injuries. We understand the trauma, its resulting problems and frustrations.

Further, we accept the behaviors resulting from BI that the general population may find inappropriate or distasteful. We understand the needs of people with brain injuries:

the need to be accepted;

the need to be recognized the need to vent;

the need to do useful work (not necessarily for pay);

the need for resources; the need to have caring friends;

and the need to live a 'normal' life.

Support groups help to meet the needs of this community of people:

we are an emotionally warm group and genuinely concerned about each another;

we allow our members to show anger and sadness over their losses and sustained limitations;

we offer a safe venue to perform and demonstrate our abilities;

we provide opportunities for social interaction, information, advocacy and service; and

we celebrate our achievements and encourage each other as we try to reinvent ourselves and live satisfying lives.

MODEL: THE BRAIN INJURY SUPPORT GROUP OF
NEWTON/ROCKDALE COUNTY

(Our support group is not typical - we have existed longer than any other group in Georgia except for the Emory chapter - but most groups offer many of the same opportunities that we do.)

About a year after my accident I was facing a life common to most survivors of brain injury:

social isolation because my doctor had pulled my driver's license, and I was confined to home most of the time;

denial of the changes in my abilities including cognitive deficits, problems with memory, planning and judgment;

frustrations with the negative impact my injury had imposed on my family; and

an overwhelming sense of loss as I began to realize that I could never again pursue a career.

Because of the positive experiences I'd had with the support group at Emory Rehabilitation Center, I began looking for a local support group to help me adjust to my new life. But I found that there was not a group in my area which is about 20 miles east of Atlanta on Interstate 20.

With the encouragement and help of my family and the Brain Injury Association of GA I decided to establish a local support group.

I arranged a meeting room with Rockdale Hospital. Their rehabilitation staff passed the word along to prospective patients, and I placed an ad in the Rockdale and Newton newspapers announcing our meeting.

We had 3 people at our first meeting: one man, my wife and me.

Soon we were having 8-10 people, and we relocated to my church, Conyers Presbyterian, so we could have kitchen facilities and provide dinner.

Our group has grown so that we have 20-30 regular attendees at our dinner meetings, and we have a mailing list for our monthly newsletter of about 150 people.

Meetings

We have dinner meetings the 3rd Monday of each month. Many groups provide our meals: the Pilot Club, Smyrna Presbyterian Church, the County Extension Service 4-Hers and other groups. When a group is not scheduled, we have a covered dish supper. My wife and I provide the entrée, drinks and paper goods, and the members - when they remember - bring an item to share.

We usually have a speaker: people from BIAG, the Brain/Spinal Cord Injury Trust Fund, attorneys, service providers, local officials and other community members who work with brain injury survivors.

Occasionally, we have fun nights: we celebrate the 4th of July with bingo/prizes, for instance.

But the main service our meetings provides is the opportunity for people with brain injury, their families, friends and caregivers to enjoy an evening with those who share their experience of trauma, adjustments, and the

physical/emotional/cognitive/social impairments of brain injury.

Our support group provides real support as we share our frustrations but also our strategies for coping with our losses.

Our meetings provide a safe venue for us to speak, share and perform at rates that the general population often loses patience with. Our meetings provide a forum for members to acquire and share information about services, resources and treatments.

Social Activities

Our support group provides opportunities for social interaction and cultural activities, including the important opportunity for romance.

Together we enjoy bingo and other games, and we have attended ball games and dances, swimming parties, cook outs and camp outs.

Many of our members have become good friends. For instance, two of our young women became roommates and enjoyed a useful, complementary relationship. One could not drive but retained a great capacity for memory and detail. The second could drive but could not remember to take her medicines. This arrangement worked very well until one fell in love and made other living arrangements.

Newsletter

We publish a monthly newsletter that is emailed to the vast majority of our members, Board members of the BIAG, and friends of our support group and the brain injury community at large.

Our newsletter includes:

- 1) a reminder about our support group meetings and other meetings;
- 2) announcements about opportunities like the Retreat/Camp sponsored by BIAG this May and free events offered by Visual Arts of GA;
- 3) recognition of our members/friends like Darren's speaking to Pilot Club last week and those who donate to help support our group;
- 4) celebration of our members' and friends' achievements like Debbie publishing her book of poetry; and
- 5) information about brain injury, new research and treatments as well as suggestions to survivors and caregivers to help them cope with the trauma of brain injury.

Advocacy

Our support group provides opportunities for people to actively advocate for brain injury issues.

We just participated with BIAG in Disability Day at the capital.

We provide our members with information, including name/addresses of legislators, to actively lobby for legislation like the establishment of the Brain/Spinal Cord Injury Trust Fund and the helmet law.

Education

Our support groups provide information to our members as well as offering opportunities for our members to share information with the public.

Through our newsletter, speakers at our meetings and sharing among our members, we provide our members information on resources, treatments and rehabilitation opportunities including grants from the Brain/Spinal Cord Injury Trust Fund.

We share recommendations of service providers and other professionals.

We explain strategies and resources for dealing with our deficits.

We also offer our members opportunities for helping to educate the general public about brain injury.

We have provided speakers to local groups (Pilots, Kiwanis, churches, hospitals and schools)

I have addressed legislative committees about brain injury issues.

We participate in local spring and fall festivals to distribute information about brain injury and our support group. At these public events we have reached people who have become members of our support group.

Service

Our support group members are ready to help each other. For instance, those who drive volunteer transportation for those who cannot drive.

Each summer we assist a local church during its mission week. We deliver materials to the work sites, help cook meals and clean up afterwards.

Fundraising

Our expenses are covered by passing the hat at our meetings. We are also supported by donations from friends of our group, and we've held yard sales and a quilt raffle.

SUGGESTIONS FOR ENGAGING YOUR CLIENT

1. A caregiver may need to be convinced to 'buy into' support group participation.

Caregiver denial, exhaustion and anger may preclude survivor participation in support groups.

But caregivers can find personal support from other caregivers in support groups, and this resource can be emphasized. (There are also special opportunities for caregivers like the Caregiver Retreat to run simultaneously with the Spring Retreat at Simpsonwoods this May.)

Because the survivor may suffer from lack of initiation, the inability to drive and/or read (announcements of meetings), and memory, the caregiver must take the initiative for support group participation particularly in the periods just after brain injury.

2. A survivor may need help with support group participation.

If there is not an effective caregiver, the survivor may need special assistance with transportation, or just remembering support group meetings and activities. Local support group leaders are happy to arrange for these needs to be met so that a survivor can become actively involved in the support group.

3. Call on the Brain Injury Association of Georgia for support group referrals, information about brain injuries and resources.

CONCLUSION

I thank you again for inviting me to share my experiences with you. I am happy to talk with you or your clients about brain injury and support groups whenever you need me. I want to leave with you contact information for me and the Brain Injury Association of GA, support groups that appear as Appendix A, and resources available through the Atlanta Regional Commission that are available as handouts.

The Brain Injury Association of Georgia

Karen Parsley, Executive Director

1441 Clifton RD NE, #114-A

Atlanta, GA 30322

404-712-5504

Tom Houchins

Brain Injury Support Group of Newton/Rockdale County

[404-316-3193](tel:404-316-3193)/hthouchins@yahoo.com

Appendix A

In addition to local support groups affiliated with the Brain Injury Association of GA there are also support groups at The Shepherd Center in Atlanta and Walton Rehabilitation Center in Augusta.

Available Handout

The Atlanta Regional Commission's local AAA (Area Agency on Aging) offices have comprehensive databases of resources for people with brain injuries and other disabilities.

APPENDIX A

THE BRAIN INJURY ASSOCIATION OF GEORGIA
STATEWIDE SUPPORT GROUP LIST

ALBANY

Tom Connelly (229) 883-3911
Ryan' Steakhouse
1224 N. Westover Blvd.
Albany, GA 31707
1st Tuesday @ 6:45pm
Tom.connelly@dot.state.ga.us

ATHENS

Floretta Johnson 706-353-1892 (h) 706-389-3550 (w)
415 Washington Dr. - Athens, GA 30601
Janice and Les Ward (706) 548-4397
Billy Geiger 770-867-1356 (after 12 noon) scalmodeler@alltel.net
Athens Regional Hospital, Bearly New Room - 3rd floor, Prince Ave,
Athens, GA 30606
3rd Monday @ 7:00pm
fbjohnson@mindspring.com

ATLANTA/
EMORY

Dr. Louise Cording (404) 371-0497
Center for Rehab Medicine,
1441 Clifton Road, Room 101
Atlanta, GA 30030
2nd Tuesday @ 6:30pm
Lcording@mindspring.com

ATLANTA/
VA HOSPITAL

VA/TBI Support Group
Dr. Inge Thomas 404-329-4654
VA Medical Center Speech Pathology Dept.
1610 Clairmont Rd.
Decatur, GA 30033
3rd Tues. at 1:30pm
Inge.Thomas@med.va.gov

COLUMBUS
AREA (INCLUDES
PHENIX CITY, AL)

"Columbus Area Brain Injury Support Group"
Doris Hicks (706) 323-5776
Shi'oh Hendricks (706) 507-4696
7204 Sesame Street
Columbus, GA 31909
Columbus Medical Conference Center, 710 Center St.
2nd Wednesday & 4th Thursday @ 6:30pm
Doris9353@hotmail.com
www.braininjurysupportgroup.blogspot.com

CLAYTON
COUNTY

Pat Buice (770) 473-7471
"Miracles Happen"
2nd Tuesday @ 7:00pm
Southern Regional Medical Center
11 Upper Riverdale Rd.
Riverdale, GA 30274
Superhope@msn.com

- COBB COUNTY**
"Unlimited Possibilities"
Martha Leatherwood (770) 428-0284
Kennestone Hospital, Outpatient Rehab Center 100 Lacy St, Marietta,
GA 30060
1st & 3rd Tuesday @ 7:00pm
supportgroup@mindspring.com
- DECATUR/
ATLANTA**
"Shepherd Pathways"
Terri Kohn (404) 603-1476
Kendra Moon (404) 248-1667
1942 Clairmont Road
Decatur, GA 30033
3rd Thursday @ 7:00pm
Terri.Kohn@shepherd.org Kendra.Moon@shepherd.org
One group for caregivers, one for survivors
- Decatur**
Cindi Johnson (404) 378-1139
"Side by Side Clubhouse"
Esp. for employment, job search skills, volunteering, etc.
755 Commerce Drive, Ste. B
Decatur, GA 30030
Mon - Fri. 9am - 3pm cindisidebyside@bellsouth.com
- FANNIN COUNTY**
Carolyn Stepp (706) 492-5308 - Home & Fax
2116 Blue Ridge
Blue Ridge, GA 30513
3rd Tuesday @ 7:00pm
First Methodist Church of Blue Ridge/ Community Bank, Blue Ridge,
GA 30313
No e-mail available - Postal only
- GRIFFIN/
BARNESVILLE
THOMASTON**
Lost and Found Support Group
Mark & Sharon Huey (770) 233-1660
58 Holly Lane
Griffin, GA 30223
1st Methodist Church, Griffin, GA 30223
2nd Thursday @ 7:00pm
sharonhuev@bellsouth.net
- GWINNETT**
Dennis Stahl (770) 965-8726
3rd Thursday @ 7:00pm
First United Methodist Church 395 W. Crogan St. Lawrenceville, GA
30045
dstahls@earthlink.net
- NEWTON/
ROCKDALE
COUNTIES**
Tom Houchins (404) 316-3193
3rd Monday @ 7:00pm
Conyers Presbyterian Church
911 N. Main St.
Conyers, GA 30012
hthouchins@yahoo.com

**NORTH
FULTON**

4 Support Groups:

- Traumatic Brain Injury and Stroke Support Group 1st Tues.
1pm - Ste. 100
- Stroke Support Group 2nd Tues. 1:00 p.m. Ste. 100
- Family Support Group (TBI-CVA) 3rd Tues. 6:45pm Ste. 400
- TBI Support Group 4th Tues.
1:00p.m. Ste. 100

Stuart Hanzman (770) 642-4236 X 41
North Fulton Regional Hospital, Medical Office Building, Suite 100,
2500 Hospital Boulevard, Roswell, GA 30076
Stuart.hanzman@aol.com

ROME

Kathy Adams (706) 291-0168 or Linda Studdard (706) 509-6623
3rd Thursday @ 6:00pm
Windwood main level conference room
306 Shorter Ave, Rome, GA 30165
No e-mail available- Postal only

SAVANNAH

Andy Patrick (912) 354-6611
George Maust (912) 927-7901
2nd Thursday @ 7:00pm
Goodwill Industries, 7220 Sallie Mood Drive, Savannah, GA 31406
No e-mail available- Postal only

**SOUTHEAST
GEORGIA**

Southeast Georgia Traumatic Brain Injury Support Group
Debra Gordon, (912) 285-7994
3rd Monday @ 7:00pm
Satilla Regional Medical Center
Telemedicine Room
410 Darling Avenue
Waycross GA 31501
debrad@wayxcable.com

**ATLANTA/
BUCKHEAD**

Minor Brain Injury Support Group
Jean Kroppa (770) 612-0612
2nd Thursday @ 7:00pm
Peachtree Presbyterian Church
3434 Roswell Road
Atlanta, GA 30305
Kroppa@bellsouth.net

**SANDY SPRINGS
(CHILDREN/
ADOLESCENTS)**

Carole Hampton (404) 250-2994
1st Monday @ 7:00pm
Children's Healthcare of Atlanta at Scottish Rite
5455 Meridian Mark Rd. NE
Atlanta, GA 30342
No e-mail available- Postal only

INCORPORATED GROUPS

**NORTH
GEORGIA
(FT.
OGLETHORPE)**

Jimmy Simpson Foundation Group
Vickie Hodge (706) 375-9520
2nd Tuesday @ 6:00pm
Ft. Oglethorpe United Methodist Church
1733 Battlefield Pkwy.
Fort Oglethorpe, GA 30742
vickieh@mindspring.com