

Over the years, we have heard from countless survivors about the importance of support groups in their recovery. Whether you are years post-stroke or only months away from your stroke, the support of others who have been there helps the emotional healing all stroke families go through. These stories demonstrate that support groups come in many flavors. If you would like help finding a support group in your area, you can call the Warmline at 1-800-478-7653 or visit our Web site at www.StrokeAssociation.org/strokegroup to search for a group based on your ZIP code.



The Healing Power of

New York's Stroke Kings by Jon Caswell

When Ted and Irma King married, they had a lot in common: Each already had children, and then they had another one together. Little did they know then that they would share a stroke diagnosis — Ted in 1986 at age 64 and Irma in 1988 at age 58.

Ted's stroke cost him the full use of his right side. Irma had problems with her left side but was able to return to work.



Ted and Irma King

During Ted's recovery he started meeting with other survivors in the hospital. "In a sense, this group became a 'band of brothers,'" said Ted, who is a veteran of World War II. He survived the Battle of the Bulge with a

shrapnel wound and frostbite on both feet.

Before being discharged from rehab, Ted and several other survivors agreed to see each other outside the hospital. "We met at a local McDonald's," Ted said. "We just drank coffee or soda and talked about what was going on in each other's lives. We talked about progress and problems we had because of our handicaps. The most important thing was the emotional support we gave each other."

The meetings soon became a monthly event.

After Irma's stroke in 1988, she became involved and the mission expanded. "We started going to the hospital and talking to survivors in the first week after their strokes. The doctors would set up meetings for us," said Irma, now 76. "That's how we started having weekly meetings at the restaurant here in Penfield, which is near Rochester in western New York."

Not long after that a second support group spun off in Greece, on the other side of Rochester, and then a third group started in Farmington, then a fourth group in Canandaigua, N.Y. Then a fifth group started in Geneseo, N.Y. All are still meeting in area McDonald's restaurants once a week from 9 to 11. Ted and Irma formed Stroke Support Self-Help Clubs of Western New York, a not-for-profit organization.

Ted started visiting rehab units, nursing homes and even personal residences in a three-county area, providing support and counsel for other survivors. "I always invited them to come to the meetings," Ted said. Today there are more than 450 members involved in the five groups.

In 2000 Ted had another stroke, which further weakened his right side and left him in a wheelchair. He also had aphasia. He and Irma continued to be active until recently.

For almost 40 years between them, Ted and Irma King have lived a simple message, which has now been shared with many stroke families — there is life after stroke.

Connection

Aphasia Support Groups

by Janet O'Connor, Speech/Language Pathologist • Aphasia and Neurolinguistics Research Lab
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While stroke support groups fill a great need in the stroke community, survivors with aphasia benefit from groups that address the many unique problems that result from disrupted language. Many general stroke groups are led by survivors or caregivers. Aphasia support groups are typically facilitated by speech therapy professionals.

Some survivors with aphasia leave the hospital without ever meeting another person who has aphasia.

"I had never heard of aphasia before my husband's stroke so I had no idea what to expect," said Paulette Westney, who was an early member of our support group at Northwestern's Aphasia and Neurolinguistics Research Lab in Evanston, Ill. "Because of his inability to find the right words and be able to express them, I didn't know what he was trying to say or needing. It was very frustrating and a difficult time for both of us. His intellect wasn't affected; he knew what he wanted to say but couldn't.

"We needed to find people who were going through what we were going through. I was shocked at how large the aphasia community is! From a caregiver's perspective, it was helpful to learn that others were dealing with and experiencing the same things I did. I was especially grateful and inspired to see people who were still improving, even after 10 or 20 years. That gave us both hope. Because of the support group, we have both learned how to live our lives in spite of the aphasia and are motivated to reach out and help others."

Our group, which I facilitate, meets on the second Saturday of every month on the Evanston campus of Northwestern University. At some meetings we have educational programs and bring in speakers who are specialists in topics like computer-assisted technology or other topics related to aphasia.

About half the meetings are less structured. In these, the group members just talk about what's going on in their lives or discuss specific topics that concern them.

"Because of the support group, we have both learned how to live our lives in spite of the aphasia and are motivated to reach out and help others."

The chance to practice speaking in an unstructured environment is one of the benefits of the programs; members never have to worry about someone trying to finish their sentences!

Whether it's in a hospital or a local church, getting a group up and running can be a challenge. For instance, it can be difficult to spread the word because people with aphasia often wind up so isolated. Here at Northwestern, we have an aphasia clinic as well as the lab, so we had a built-in group of people who wanted to get involved. The survivors wanted to get the support of other survivors as well as give support to others with aphasia.

After we had developed our core group, we spread the word through other stroke groups and to speech therapists in the Chicago area. Today we have 60 members. We average about 25 at monthly meetings.

After two years together, our members are ready to reach out to others with aphasia. Following the lead of Living with Aphasia, a Madison, Wis., support group that sponsored the Midwest Regional Aphasia Conference in 2004, our Northwestern group is sponsoring a second conference this Sept. 15–17, 2006, in Northbrook, Ill. This is a great opportunity for survivors with aphasia to help other survivors with aphasia, and the planning is well under way. We expect about 200 survivors, caregivers and speech therapy professionals to attend. For more on this conference, go to www.midwestaphasiaconference.org or www.communication.northwestern.edu/csd/clinics/aphasia/ or call 847-467-7591.



“Not many people can say they have two families,” said survivor Cindi Twickler of her online stroke support group, the AOL Strokechatters. Cindi, 47, was speaking at their annual get-together held in Fort Worth, Texas, this past May. “We are lucky. We honor each other, we support each other, we guide each other, but most of all, we relate to each other, and that makes our personal tragedies easier to cope with.”



The AOL Strokechatters is the Internet child of survivor Don Aitro, 72, of Fort Worth. The Strokechatters is a private chat room, and membership is required. Membership provides access to the chat room, message board and e-mail. “I started my first chat room on AOL in 1998,” says Don, who uses a wheelchair. “It was a public chat room, and people came in who weren’t survivors or caregivers. I don’t know why they want to do that. You learn to spot them right away, but still it

created problems, so I started a private chat room last year so we can control it better.”

Donna Ricci, 52, of Ft. Lauderdale had her stroke 27 years ago. Although she is in a wheelchair and has aphasia, she has raised two daughters and lives independently. “I was a member of a support group in Ft. Lauderdale,” she says, “but it only meets once a month, but with this group, we meet every day. We talk about personal stuff and stroke stuff. Because of them I have another family who’s interested in my life. They are there for me, day or night. We don’t just talk on the computer, we talk on the phone. Many of us visit in each other’s homes.”

Many of the AOL group have known each other from other chat rooms, but they have only begun having annual gatherings recently. The Fort Worth weekend was their third, and they had it there so Don could attend. Donna hosts next year’s in Orlando.

“Stroke leaves many people with unusable parts or a different look,” Cindi Twickler said. “We just don’t seem to fit the same anymore. It’s like putting together a puzzle for months, and when you get to the last piece, it’s missing! All of us are those last pieces, but when we go to our group, we all

fit fine. No one notices that foot we drag or that arm we prop up on the table or that crooked smile. We all just fit. We’ve found a special place that allows us not only to receive help, but it allows us to focus on issues that others are facing and help them.”

The AOL Strokechatters has about 40 members. If you are interested in joining this group, you can contact Don Aitro at Don349@aol.com. You must subscribe to AOL in order to participate in Don’s group.

“Once you have a stroke, a lot of your friends disappear, so you’re left on your own,” says Don. “We survivors have our emotions right under the skin, and they come out easily when we come together. When we get in that chat room, we’re all the same, the disabilities disappear.”

For information on other online support groups, visit our Web site at www.StrokeAssociation.org. Type “stroke support groups” in the Search window. **SC**

What’s in It for You

The stroke support group at Mercy Hospital in Iowa City, Iowa, will celebrate its 20th anniversary in 2007. Like many groups, it was started by a stroke family who wanted the counsel and support of people who were on the same journey to recovery. Maintaining a support group for so many years takes a lot of dedication and energy from stroke families and the allied health professionals who serve them.

Recently the members of the Mercy Hospital group shared their top 10 reasons for attending the group:

- Learning to think as a survivor, not a victim
- Sharing and learning with other people
- Keeping hope in your heart for the future
- Realizing that stroke affects people differently
- Being with people who understand your situation helps you heal
- Helping overcome depression
- Learning what to expect
- Gaining inspiration from others
- Discussing meaningful topics and being with others
- Celebrating the little and big successes that survivors have

— Submitted by Mary McCarthy, Patient Education Coordinator, Mercy Hospital, Iowa City, Iowa