

Long Beach Press-Telegram (CA)

Offering help, hope after a stroke

June 1, 2008

Section: NEWS

Edition: MAIN

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Caption: Jeff Gritchen/Staff Photographer

Art Gottlieb, a former attorney and now a published writer, had a stroke more than 25 years ago and said he went through a difficult rehabilitation. As a facilitator at weekly meetings at the Stroke Center of Long Beach, he helps others cope with life after a stroke.

One person tells of becoming lost during a walk near his home. "It's really frightening," he says. "You don't know what to do. You just stand there."

Another says, "I get angry very quickly. I cry very easily."

A third confesses, "I want to get a job where people don't know I've had a stroke."

It is Tuesday morning at the Stroke Center of Long Beach, the name given to the two- to three-dozen people who actually meet at the California Heights Methodist Church in Bixby Knolls. Some come to the weekly meetings in wheelchairs, some on canes and crutches, some walking on their own.

All seem motivated by the need for togetherness, the feeling of being with others who have shared the experience of weathering a stroke.

In each case, the stroke came without warning and left the individual forever changed. Some are fighting to regain their power of speech, and to the visitor are difficult to understand. They tell their stories and report their progress with help from colleagues and facilitators.

'Victim' label shunned

Earlier this year, I spent three consecutive Tuesdays monitoring Stroke Center meetings, which are usually about an hour long. Referring to members on my first visit as "victims of stroke," I was quickly corrected. "We are not victims, we are survivors," insisted one group member. The difference is vast. "Victim" carries a hint of hopelessness, but "survivor" portrays a future of almost infinite possibility.

To my surprise, the members almost immediately asked me to recount my own experience when, on Nov. 30, I experienced a transient ischemic attack. Somewhat similar to a stroke, a TIA leaves no permanent damage and usually resolves itself within a few hours. However, it is seen as a warning that a full-fledged stroke could be on the way.

They wanted to know the symptoms of my TIA (inability to talk, think, or measure time; I kept thinking it was 1987) and how quickly I got to the hospital (almost immediately, thanks to Dr. Larry Drum's advice and my wife's penchant for driving like A.J. Foyt.)

With a couple of exceptions, you will not read the names of stroke survivors in the paragraphs that follow. Many aspects of stroke seem quite private to some who survive it. As one Stroke Center member said, "I want to get a job where people don't know I've had a stroke. I don't want the people I work with to treat me like I'm some sort of freak."

I was motivated to visit the Stroke Center by my own experience and by my friend, Art Gottlieb, who suffered a stroke more than 25 years ago and went through a difficult rehabilitation. A former attorney and now a published writer, he serves as a facilitator for the center. Under a pseudonym, Art has written a privately published book on life after stroke.

Basically, stroke involves an interruption of the blood flow to the brain. Because of this, brain cells are damaged and die. Since different parts of the brain control different functions of the body, the key to stroke damage lies in which part of the brain has been affected. One part, for example, deals with thought processes that involve numbers.

While otherwise on the mend, one Stroke Center survivor, for example, is struggling to gain accreditation as a history teacher. He needs a college degree, but cannot cope with a required algebra course that stands between him and that degree. His mathematical skills have been lost. His only hope is that somehow rules will be bent.

"Every stroke is different," my friend Art wrote in his book, "And the ways they affect an individual are infinite. But there are common threads which run through the singular tapestries of illness created by dead brain cells."

He recalls the experience of telling a speech therapist what part of his brain was damaged. Based on hearing only that, the therapist told him, "You talk too much, act in ways which are socially inappropriate, have difficulty arriving at correct conclusions from a set of facts, fatigue easily, fight with your wife daily, can't balance a checkbook and have trouble backing out of the garage."

She had described the stroke-damaged Art to the letter. Her description gave him a blueprint of things he needed to work on during his next quarter-century of rehabilitation. He has been involved with the Stroke Center, as a member and later a facilitator, for 25 years.

One common denominator of stroke is that it comes on suddenly. "One night, I went to bed able-bodied and woke up handicapped," says TV-radio personality Dick Clark, who experienced his stroke in 2004. "It happened that quickly. ..."

Two brains in one

As many of us know, the brain is divided into right and left sides or hemispheres, each controlling certain functions and behaviors. The right hemisphere controls muscles on the left side of the body, the left hemisphere controls muscles on the right side. Thus, damage to one side of the brain will result in damage to the opposite side of the body.

Because the right side generally controls spatial concepts, visual imagery and music while the left side dominates language, math and logic, pinpointing the area of cell damage gives medical practitioners the ability to know what to expect from stroke victims.

Art and others have amazed me with their ability to notice, almost at a glance, whether a survivor's stroke affected the left or right side of the brain.

The members represent people from virtually every walk of life who have become diminished by the vagaries of limited blood flow and cell damage. Art was an attorney. The circle of stroke survivors he helps includes former teachers, clerical workers and a one-time police officer. One of the first things Art taught me about stroke is that it can be incredibly precise. As his book notes, "With cell-life loss in the left hemisphere, the stroke survivor may have trouble with pronouns. He wants to refer to his friend, Jim, but in the process of reaching into the grab bag of his speech center he may select 'he' or 'she' or 'her' or 'it' or 'them' As a further complication, the choice is random, even in the same sentence.

Why they join

Motivation for taking part in the Stroke Center is almost as varied as the patients and the assorted types of stroke they have survived.

One member says he is driven by curiosity to see how other survivors are doing. "I came here because I was a stroke survivor and needed the help the group offers. Now I come here because I want to see how well they are doing."

Survivors include former teachers. Another, who was in clerical work before her stroke, hopes to return to that field after having survived a stroke in April of last year. "I heard about the center while I was still in the hospital," she notes.

Still another says, "This is where I get all my information. That's why I hate to miss a week." He feels guilty about having missed the previous week's meeting. The member, whose stroke was in December 2005, admits to good and bad days.

"You have some good moments when you think you may get back to square one. And there are moments when you think it's the beginning of the end."

Stroke is sometimes discussed with tears, sometimes even with laughter. One survivor, for example, admits he worries about falling. Another responds, "So do I. You'd be difficult to catch."

How long it takes to rehabilitate depends on a variety of factors, including the extent of cell damage and the individual's willingness to work at it. By way of example, a survivor who lost the use of his hand (and more) tells of his efforts to regain the use of the hand by squeezing a rubber ball.

"You may have to squeeze it a thousand times. You may have to squeeze it two thousand times. You may have to squeeze it three thousand times. But on the 3,001st, you may feel it start to give."

For another survivor, a high-school halfback 50 years ago, the satisfaction of having joined the group lies in outwitting his physician, "My doctor told me I would never walk again, but I showed him. I came to the group because I had been told about it at St. Mary's (Medical Center). I came, I saw, I conquered."

For some, the motivation to join the group was simple. "I came here because I didn't understand why I had a stroke. And it is good for me to find out I'm not as bad as some others." Others find therapy in numbers. "Everybody in the group has had the same problem; you're not unique.

Says another, "You have a lot of friends here who care about you."

Divided by three

While members are free to say what they wish, Stroke Center meetings are carefully crafted. Members meet together, then split into three groups: one for survivors over 60, another for younger survivors (stroke can hit at virtually any age) and a third for caregivers: spouses and others who have the often difficult and frustrating tasks of caring for the survivors.

After sitting in on the first two groups, I became entranced by hearing the caregivers. "The strain on them is enormous," says Art. "They have been transformed in an instant from spouse to full-time nurse, head of household and major source of income."

Art's wife, Shirle, never says that "Art had a stroke." She says, "We had a stroke." The stress on the caregiver is evident in the voice of one spouse who says, "It took about five years just to get his medications straightened out. He's come a long way from being a vegetable, which is what he was. He's not the man I married, but life has gotten better. We still have our down times, but there are positive things that have come out of this.

Another caregiver says, "I'm so afraid to leave him alone. He wants to be independent. That's what I want for him; like the time he wanted to go have coffee with a neighbor. I threw up when he left, but I had to let him go."

Says another wife, "He likes to do every single thing the doctor says. I don't want to do anything the doctor says. I like all the herbal stuff."

Quarter century of help

The Stroke Center has been around for more than 25 years. One of those who has been there since the beginning is Mary Buck, a Lakewood woman who served as the group's coordinator until retiring in December.

"About 27 years ago, some professionals in our area decided there must be some place for stroke survivors to come to for rehabilitation after being back in their homes," says Buck. "There was a program in Los Angeles and the director of that program helped get us started."

Initially the survivors met at Pacific Hospital, then moved to the Church of Christ on Atlantic Avenue. "When we outgrew that," says Buck, "we moved to the California Heights Methodist Church."

Buck also notes, "The center runs a hospital visitor program in which survivors who are well on their way to recovery go into the hospitals to meet with stroke patients."

The center's new coordinator is Dr. Jane Claus. Its director is Norma Norris, who is assisted by Gary Huffman. Norris stresses the importance of stroke information. And notes that "80 percent of strokes are preventable."

For further information, call
562- 537-0556.

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