The Long Walk Home
Stroke Survivor Keeps the Faith, from “Blinking Eyes” to Talking, Walking and Independence

“I took for granted that I had a clean bill of health, before my stroke,” says Marilyn Lewis. “I was an active member of Curves, eating my oatmeal, and managing my cholesterol, hypertension and blood pressure with medications. I thought I was doing everything right.”

Lewis, a former accountant at North Carolina State University, had little reason to suspect a major health problem. Additionally, she and her family were not prepared to recognize the symptoms of her stroke, which appeared suddenly, and without pain. No one in her family had ever suffered from a stroke.

“I was at my parents’ house in Bladenboro, about 15 miles south of Lumberton, the Saturday before Father’s Day,” she remembers. “I cooked lunch, and we sat down to eat in the family room. Up to that point everything was fine.”

After eating lunch, Lewis began changing the linen on her father’s bed. “All of a sudden I bent over and felt a tingle in the back of my neck,” she recalls. “It didn’t hurt; just a tingle. I sat down and said, ‘Mama, something’s wrong.’ Mama said, ‘Just rest, baby.’”

But Lewis already felt her legs going “out from under” her when she tried to stand. Her brother, Lee, picked her up and laid her on the couch. He then noticed she had trouble swallowing, and decided to call 911.

“Thirty minutes later, an ambulance came to take me to Southeastern Medical Center in Lumberton,” Lewis remembers. “I arrived at 2:30 PM Saturday afternoon.” But it was not until after 3:00 AM Sunday morning, more than twelve hours later, that Lewis was put in a room and stabilized. “That was the weekend, so I didn’t see a doctor at the rural hospital until Monday,” Lewis recalls. “On Monday, they ran the first and only tests on me, including an MRI. My family was told I had suffered a brain stem stroke, and that there was not much hope.”

Lewis’ family immediately made the decision to transfer their loved one to UNC Hospitals, where more facilities existed.

“All I could do was blink my eyes when I first transferred to UNC,” Lewis recollects.

While Lewis was still in the UNC Stroke Center, Antje Thiessen, a speech therapist on UNC Hospital’s Inpatient Rehabilitation Center team, worked with Lewis using a communication board.

“I would look at the letters and my family and Antje would try to figure out what I was saying,” Lewis relates, looking back on those days. “I communicated, ‘Antje, can you fix me?’”

With Thiessen’s help, Lewis came to the Rehabilitation Center for more intensive and comprehensive therapies.

“In rehab at UNC we worked really hard,” Lewis continues, “but we had so much fun, because everyone is so encouraging. The therapists, nurses, and doctors focused on the things I could do.”

Lewis also received encouragement from her family, as well as from NC State colleagues. “My family always stayed with me. They took turns during the night.”

Lewis continues to look forward. “I want to be able to take care of myself,” she says. “My goals are to walk by myself and to drive by the end of this year.”

Now in her own apartment, and volunteering to help aspiring therapists learn about stroke patients, Lewis also credits her faith as a major healing factor. “When I was in the hospital and could not speak, my faith in God brought me through, helping me focus on the next step to overcome this turn my life had taken. I know I’ll get my independence back if I keep working hard and take it one day at a time.”

UNC Rehab Center, Stroke Therapy Featured on TV

Teena Dixon (left) and her physical therapist, Susan Gisler, PT, DPT (right), talked with local NBC-17 health and fitness reporter, Julie Henry, about the benefits of exercise in stroke therapy.

To watch the video and read the WNCN article, see our news column on the PMR web site: www.med.unc.edu/phyrehab

INSIDE THIS STROKE ISSUE:
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Dear Friends,

Along the theme of this stroke issue, I am proud to announce that our Inpatient Rehabilitation Center continues to surpass the national average in the functional improvement of stroke patients within the same length of stay.

As always, our external communications reflect the heart of our mission by highlighting endeavors such as Dr. Patricia Gregory’s research and clinics in the “stroke belt” of North Carolina (featured on page 4). Projects such as her Lumberton outreach require additional funding not provided by the state. If you would like more information, please contact our director of development, Nicole Pratapas, at 919-966-8494 or nicole_pratapas@med.unc.edu via email. Any amount will help stroke patients become more functional along the continuum of care. Thanks to all of you who donated through our previous issue, and for your continued support.

I also am excited about our ability to continue the dialog from these newsletters through our web site. We encourage you to learn more about our patients and programs on our new pages: www.med.unc.edu/phyrehab
As we continue to grow in our external communications, please feel free to offer your suggestions and feedback using the self-addressed, postage-paid envelope included with hard copies of this issue, or drop us an email at rehab_reader@med.unc.edu any time. You also may offer comments and suggestions, or give a donation, directly from our website.

With this stroke issue we continue our thematic series. In the near future, look for issues about pediatric rehabilitation and spinal cord injury, among others.

Michael Y. Lee, MD, MHA
Professor and Chair

Acute rehab is becoming a shorter experience for patients due to variation in insurance coverage. With this in mind, members of the interdisciplinary team at the Inpatient Rehabilitation Center aim to use managed care to the patient’s greatest benefit.

George Atkinson, MD, a stroke rehabilitation specialist, makes sure that patients within the Inpatient Rehabilitation Center benefit not only from state-of-the-art therapies, but from the wisdom of all participants in recovery.

“The biggest challenges to people recovering from stroke include being patient, especially about neurological and functional recovery, getting through down times, and working on lifestyle changes to prevent a second stroke,” Dr. Atkinson says.

Care conferences give all participants a chance to discuss the sudden and often overwhelming changes – in lifestyle, communication, role in the family, and income – after a stroke or other catastrophic event.

Part of Meyer’s job is to understand the patient’s social network as well as his/her level of independence prior to hospitalization. This provides insight into opportunities and barriers to future independence.

Typically individuals continue some course of therapy after discharge from acute rehabilitation. Meyer provides information on options for continuing care and guides the patient and family in the decision-making process. Meyer also provides information about resources and community support groups tailored to the individual’s geographic area.

“Support groups help patients gain more control of their lives,” Meyer notes. “Patients and families begin to educate themselves further. They regain a sense of hope. They come to the awareness that there are many things in their lives they can change.”

The support group provides a kind of model for group trust, opening the door to social involvement in the community. Many patients stay in touch with members of the rehab team while visiting outpatient clinics, volunteering, attending support groups, and by sharing progress and lessons through writing.

“We had a patient who started his recovery from zero,” Meyer recalls. “After discharge, he kept in touch with us by email. He also shared deeper reflections: how his experience changed his sense of what’s important in life.”
After a stroke it is not uncommon to feel that one’s plans for life have been forever changed…

“It was like waking up in a foreign country…Suddenly I found myself struggling to do the smallest things, like feeding myself or tying my own shoe…”

“I had to depend on my wife for everything—she dressed me in the morning and took me to the bathroom in the middle of the night…”

These are just a few of the many challenges that individuals might face on a daily basis when recovering from a stroke.

Having to depend on family, friends, or even strangers to help with everyday activities like bathing or dressing can create feelings of frustration or embarrassment.

In addition to the physical changes, many of the stroke survivors we meet also describe emotional changes, such as “feeling different” after their stroke.

Depression following a stroke may be more common than you might think. In fact, it is estimated that over one-third of all stroke survivors experience depression following stroke. The good news is that depression can be treated, and research suggests that treating depression after stroke may result in better cognitive recovery as well.

The rehabilitation treatment team or other qualified healthcare professional can provide you with the information you need to know about treating depression after stroke.

Here are some local resources to consider:

 UNC Stroke Support Group
For stroke survivors and caregivers  
2nd Wednesdays, 1:00-2:00 PM  
UNC Wellness Center, Meadowmont 
919-966-8044

UNC Stroke Support Group
For stroke survivors and caregivers  
3rd Wednesdays, 1:00-2:00 PM  
UNC Wellness Center, Meadowmont 
919-966-9501

Department of Physical Medicine & Rehabilitation Psychology Services 
919-966-8812

Support group information is updated monthly under the “Local & Global Outreach” page on our web site.

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Dr. Karla Thompson (seated, right) with Inpatient Stroke Mentors. For more information about this motivational program, available for inpatients at the UNC Rehabilitation Center, please see our web site.

Depression may be one of several symptoms that can occur after a stroke. George Atkinson, MD, assistant professor in Physical Medicine & Rehabilitation, advises that you also monitor these other complications with your primary care physician after your stroke:

- Spasticity (tightness) in a weak arm or leg, especially if it interferes with function
- Skin breakdown, especially if the patient is less mobile
- Medical conditions such as high blood pressure and blood sugars
- Pain in an affected limb

Call 911 if you experience the following:

- Worsening weakness or numbness
- Worsening speech
- Worsening mental status
- Seizures

Look on our web site for more information on stroke:

- How to prevent a stroke
- Common symptoms at the onset of a stroke
- What Marilyn Lewis (featured on our cover page) taught a nurse and therapist about stroke patients
- Inspirational journeys, from our stroke mentors

Go to: www.med.unc.edu/phyrehab (features column)
Physical Medicine & Rehabilitation Research

PMR Assistant Professor Addresses Stroke Rehabilitation Disparities in North Carolina
By Patricia Gregory, MD, and Kim Faurot, MPH, Research Associate

The high rates of stroke in the southeastern region of the United States earn it the epithet “the Stroke Belt”. Rates of stroke in North Carolina (NC) are so high that it ranks eighth in stroke prevalence in the US, with 26,846 strokes in 2005. Within NC, stroke rates are highest in the eastern part of the state, especially among minorities; both African Americans and American Indians have higher rates of stroke than whites.

Access to the best stroke care is limited in rural areas. Only half of the state’s population lives near hospitals that provide full stroke care services; only two of the 13 certified primary stroke centers in NC are located in the rural south and eastern region of the state where stroke prevalence is highest.

Stroke complications are minimized in a primary stroke center because of availability of resources. Patients have access to a team of rehabilitation professionals and can receive early intensive rehabilitation to ensure that they regain as much function as possible.

Patricia Gregory, MD, assistant professor in the Department of Physical Medicine & Rehabilitation at UNC, has committed herself to evaluating and improving access to stroke rehabilitation among the underserved.

She has interviewed dozens of stroke survivors in rural areas to find out about their rehabilitation experiences after a stroke. In addition, she has examined stroke care processes in a rural hospital.

Her work confirms the findings that stroke rehabilitation care is limited for people in rural coun-
ties with greater minority populations. In addition, because rehabilitation and stroke neurology specialists are not available in rural areas, rehabilitation and stroke prevention care often is not coordinated.

To address this problem, Dr. Gregory has applied for grant funding to provide stroke neurology and rehabilitation consultations via telemedicine.

Telemedicine technology allows patients to see a specialist without leaving their community. Patients in rural NC can have a visit with Dr. Gregory, a PM&R specialist, andAna Felix, MD, a stroke neurology specialist, by two-way camera over a secure internet line. This way, Dr. Gregory can review rehabilitation progress and make recommendations to improve recovery. The patients also can ask Dr. Gregory to address any questions they might have.

The Department of Physical Medicine and Rehabilitation already is using telemedicine to ensure that children with disabilities have access to a pediatric rehabilitation specialist, Joshua Alexander, MD, associate professor. Dr. Gregory plans to use a similar system to provide patients in rural counties access to the same stroke rehabilitation care we have here in Chapel Hill.

For more information about how to help fund the stroke telemedicine project, contact Nicole Pratapas, director of development, at 919-966-8494 or nicole_pratapas@med.unc.edu via email.

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