




**Team**





Patients at UT Southwestern's multiple sclerosis center receive more than just cutting-edge medical care. They receive help in living better lives while they battle their debilitating disease.

# TLC

*Total Life Care*

BY DEBORAH WORMSER

Susan Sides adored helping patients as a nurse at Children's Medical Center Dallas. She held increasingly responsible positions there for more than 15 years after her first episode of multiple sclerosis and even after a 2002 stroke, all that time presenting a brave facade.

"I hid the MS from some of my co-workers and tried to hide it from my daughter, who was 9 when I had the stroke. I tried to act normal, but I wasn't OK. I was under a lot of stress," recalled the 46-year-old Frisco, Texas, wife, mother, and health care professional.

Mrs. Sides and many MS patients like her have benefited greatly over the years from Dr. Elliot Frohman's decision to move Dallas in 1995 as Director of the new Multiple Sclerosis Program and Clinical Center at UT Southwestern Medical Center.

Dr. Frohman, Professor of Neurology and Neurotherapeutics and of Ophthalmology, said colleagues across the country wondered why the former chief resident of neurology at Johns Hopkins Hospital would put his promising research career on hold to concentrate on patient care, which consumed his time for the first four years of the clinic's existence.

"It was very clear that this was a place that was very serious about establishing a major center for clinical care, for research, and for education," he said, explaining his conviction that UT Southwestern would help turn his dream of a comprehensive-care, clinical-research center into reality.

TLC has served more than 180 patients since its creation in September 2011 with seed money from the National Multiple Sclerosis Society.

MS is the most common cause of progressive neurological disability in young adults, affecting an estimated 400,000 people of all ages in the United States, according to the National Multiple Sclerosis Society. An autoimmune disease of unknown origin, MS causes inflammation that damages or destroys the fatty myelin layer that covers nerves in the central nervous system. MS can affect virtually any part of the body and every aspect of family life.

That's why the 5,400 patients and their families come to UT Southwestern's MS clinical center with questions that range from "How can I keep MS from harming my marriage?" to "Why can't my mom push me on the swing anymore?"

#### **Integrating research, care**

To answer such questions while providing the cutting-edge medical care for which it is known, UT Southwestern's MS clinical center has pioneered a multidisciplinary team approach that addresses the patient's adjustment to his or her MS, as well as treating the disease itself. By applying the same scientific rigor to improving the patient experience that it does to medical research, UT Southwestern physicians draw on the unique strength of an academic medical center to integrate research and clinical care in a seamless, self-sustaining cycle of innovation.

The 70 staff members at the research and clinical center show off that model several times a year at the only nationally funded MS treatment training program. The National Training Program for the Comprehensive Care of Individuals with Multiple Sclerosis recently marked a milestone: 1,000 caregivers, including 800 physicians, have received training through the program.

Dr. Frohman co-wrote the congressional appropriations bill sponsored by former Sen. Kay Bailey Hutchison that funded the training program from 2001 to 2006, when the National Multiple Sclerosis Society took over sponsorship.

The MS center's neurologists see adults with MS and related demyelinating disorders at its location on the UT Southwestern campus and at Parkland Memorial Hospital. In addition, they treat children with those disorders at the pediatric MS clinic at Children's Medical Center. To handle that volume, the doctors depend on a multidisciplinary team that includes physicians, nurses, social workers, technicians and support staff, and, most particularly, physician extenders such as nurse practitioners and physician assistants, not to mention the clinical trials and basic science research staff.

Patients generally see their neurologist once or twice a year. For routine visits, the patients can choose anyone on the team. The comprehensive treatment approach gives patients a variety of perspectives, Dr. Frohman said.

The system worked well for Mrs. Sides for many years. By 2011, however, she was on long-term disability – not because of the stroke, which had few residual effects, but because of her progressing MS.

Dishes would slip from her tingling fingers and crash to the floor. She was having difficulty walking even with a walker or cane. Her memory became cloudy, especially when she became hot or tired, a phenomenon called Uhthoff's, which often accompanies MS.

#### **Stress on the family**

All of those things put stress on her family, as did a series of personal problems. The stress of MS doesn't free people from the pressures of normal life, she explained.

Then she suffered two serious falls in a matter of months, breaking her right leg so badly it needed seven screws and a metal plate. Then she broke her shoulder. She went on disability and was unable to work at the job she loved.



Although she felt alone, she wasn't. The team at UT Southwestern's MS center was on the case.

The entire multidisciplinary care team meets every Wednesday morning to brainstorm new strategies for their most challenging cases. One morning, the discussion focused on Mrs. Sides' case. The team members agreed she was a high-risk patient who might benefit from the MS program's new treatment option: the Total Life Care clinic (TLC).

TLC has served more than 180 patients since its creation in September 2011 with seed money from the National Multiple Sclerosis Society. The TLC clinic seeks to remove every possible barrier that could interfere with treatment, from transportation to family problems. Its staff hopes to conduct research into whether the TLC approach can save health care dollars by keeping high-risk patients out of the hospital.

"MS is a progressive condition, and life is progressive," explained Diana Logan, the nurse practitioner who spearheaded the program with Dr. Frohman. Sometimes life gets in the way of the MS treatment, and a global approach is required.

In the regular MS center, patients see any one of the team members periodically in visits that last about an hour. TLC patients see as many doctors from different disciplines as possible, all on the same day. The first visit lasts about four hours.





“MS is a progressive condition, and life is progressive.” — Registered Nurse Diana Logan with MS patient Susan Sides

“For patients who are on crutches or are wheelchair bound, it is difficult to get to multiple doctor appointments. Even when the area is wheelchair accessible, it can be too exhausting for patients with low energy. We help them cut through those barriers by having as much care as possible in one place,” Mrs. Logan said.

#### **A health passport**

When patients arrive at the TLC clinic, they receive a slip of paper that becomes their global health passport. In addition to the MS center’s social worker, nurse practitioner, and physician assistants, the TLC clinic also offers a physical therapist for gait assessments and a registered dietitian for nutritional counseling. Like everything about MS, even its nutritional aspects are complex: Some MS patients deal with obesity, while MS makes others dangerously underweight, Mrs. Logan explained.

It’s Monday, 7:30 a.m., and the first thing Mrs. Logan does for her TLC client is to listen. Intensely.

She begins by asking: “What does this disease keep you from doing? What bugs you the most?” She then carefully follows a checklist

that asks about mobility, mood, memory problems, energy level, etc., in order to get a comprehensive view of the patient’s condition, problems, and possible goals.

“It really doesn’t matter how smart I think I am or how smart any of us think we are or what we want the patient to do,” Mrs. Logan said, echoing one of Dr. Frohman’s oft-quoted treatment pearls. Often by the time she’s finished her detailed assessment, she’s changed her mind about what the goals should be.

“What is most important is that the TLC goals are set by the patient,” she added.

Together, Mrs. Logan and her patients brainstorm strategies to achieve those goals. Next, the patient takes the global health passport to another member of the team and the process repeats. At the end of the day, the patient has a fully signed passport, a printout of goals and strategies, and an appointment in three to four months.

“They are very compassionate, and they treat me like I’m the only person they have to worry about,” Mrs. Sides said. “TLC is totally brilliant because it incorporates the four things that are very important in your life when you have MS: treating your symptoms, your emotions, your diet, and your physical activity.”





"Since 1993, there has been an explosion of treatments for MS, making this the most hopeful time in history for patients with demyelinating disorders."

— Dr. Elliot Frohman

Mrs. Sides says her goals included getting out of the house, losing weight, and exercising her core muscles, which are essential to balance. She now gets out regularly to participate in a Bible study group. She's eating more nutritiously and has started to exercise. She praised the free yoga video she received at the MS clinic, which features a professional yogi plus Dr. Frohman in gray sweats and a white T-shirt demonstrating stretches and poses adapted to MS. "Dr. Frohman's a good yogi," she said with a laugh.

Achieving her goals made her feel better physically and reminded her that she is basically an optimistic person. As a result, she said she's had more energy to face life's everyday stresses.

For questions that arise between visits, Mrs. Sides sends an email to members of her care team through MyChart, UT Southwestern's online communications link. She always gets a quick response.

### Empowering others

To understand how the TLC program developed, it's important to know a few things about Mrs. Logan and the ways in which Dr. Frohman empowers those around him.

Mrs. Logan was a hospice nurse for many years before coming to UT Southwestern.

"I would get all these referrals to these elderly people who were supposedly dying. When I'd go to the person's house, the patient would have a refrigerator filled with moldy food. He or she would be falling, have shoeboxes of medications from multiple doctors, and sometimes hadn't had a bath in weeks," she recalled. She would provide a bath, set up a medications box, arrange for food delivery and transportation to the doctor, often with astounding improvements.

When she interviewed for the MS clinic job fresh out of the nurse practitioner program at UT Arlington five years ago, she told Dr. Frohman that she didn't know anything about MS.

"Never mind about MS, I'll teach you that," Dr. Frohman answered. "Can you take care of my people?"

Once on campus, he encouraged Mrs. Logan to apply for the John Dystel Nursing Fellowship from the National Multiple Sclerosis Society, which paid half her salary for six months while she studied how MS patients are treated across campus, "not just from a treatment plan perspective, but how they were treated as people – attitudes toward MS patients, how aspects of the disease were handled by other disciplines, even how similar chronic, debilitating disorders were treated," she said.

Mrs. Logan returned to Dr. Frohman and outlined the TLC clinic idea. He liked the intensive care model for high-risk patients.

### Conducting basic science research

In addition to participating in clinical trials, the MS center conducts basic science research in a consortium that includes Johns Hopkins School of Medicine; the University of California, San Francisco, School of Medicine; and New York University School of Medicine.

That research focuses on the retina and optic nerve, located at the back of the eye. Members of the consortium and the MS center's eye lab have published research that helped identify quantifiable damage to the optic nerve as a proxy for damage to nerves in the brain and spinal cord.

The group's ongoing research seeks to determine whether monitoring the status of the optic nerve could be used to find out the effectiveness of the disease-altering therapies that have revolutionized MS care since the first such therapy was approved about 20 years ago.

Before 1993, doctors could address disabilities caused by MS, and they could often use high doses of steroids to stop an MS flare up once it began. But nothing could keep the disease from progressing.

"Since 1993, there has been an explosion of treatments for MS, making this the most hopeful time in history for patients with demyelinating disorders," Dr. Frohman said.

Dr. Douglas Woo, a neurologist in private practice in Ohio, enrolled in the MS center's national training program as a neurology resident trying to choose his career path. The intensive training convinced him to return to Dallas in 2005 for a one-year clinical fellowship under Dr. Frohman. He credits the fellowship with providing him the clinical skills necessary to deliver a full range of high-level care to both pediatric and adult MS patients.

Dr. Woo said he was impressed with how much the program had grown when he returned for a visit in 2012. He estimates that 75 percent of the clinical and administrative skills he used for several years as director of the neurology residency program at the Medical College of Wisconsin in Milwaukee was acquired from his training under Dr. Frohman.

"It's not just caring for MS as a disease, it's caring for MS people, MS families, and their communities," Dr. Woo said.

Dr. Frohman has co-written more than 200 scientific reports in publications such as *The New England Journal of Medicine* and *The Lancet*. He has written more than 20 book chapters and been singled out for more than a dozen teaching awards. Most recently, the Accelerated Cure Project for Multiple Sclerosis honored him with its 2012 Physician of Distinction Award for endeavors that have helped thousands of MS patients.

As he was leaving the stage in Boston after receiving that award, a woman in a wheelchair stopped him. She explained that her doctor returned from a UT Southwestern training session and urged her to try self-catheterization again despite a history of failures. The latest methods and equipment worked, freeing the young woman from wearing a urine-collection bag and giving her unexpected freedom and independence.

"I don't know you and you don't know me, but I want to thank you for making my MS doctor a better doctor," the young woman told Dr. Frohman.

*Dr. Frohman holds the Irene Wadel and Robert I. Atha, Jr. Distinguished Chair in Neurology, and the Kenney Marie Dixon-Pickens Distinguished Professorship in Multiple Sclerosis Research.*



Diana Logan (standing) meets weekly with other members of the TLC team to brainstorm strategies for their most challenging cases.

