



Creating a Better Story

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Sometimes there are no happy endings.

Sometimes there are only better stories.

Better because someone showed compassion.

Better because someone helped a person maintain
dignity through unimaginable circumstances.

Creating better stories is what
Kimberly Goslin, M.D., Ph.D., is all about.



Dr. Goslin is a neurologist who specializes in treating people affected by amyotrophic lateral sclerosis, also known as ALS or Lou Gehrig's disease. This progressive disease of the nervous system causes motor neurons – the communication system between the brain and the body's moveable parts – to deteriorate and die. As a result, muscles in the arms and legs as well as those used for speaking, swallowing and breathing waste away.

Patients gradually lose their ability to walk, use their arms, talk, swallow and even to breathe independently. In later stages of the disease, patients become totally paralyzed. Some rely on permanent ventilator support in order to

breathe. Despite progressive paralysis, patients' minds remain sharp and their senses – sight, hearing, touch, smell and taste – unaffected.

It was one particular patient who prompted Dr. Goslin to devote her career to ALS.

"During my neurology residency, I met a wonderful man who had ALS," recalls Dr. Goslin. "Despite all that medicine has to offer, we could do so little for him." Futile from a curative perspective, his situation ignited her desire to create better stories for patients like him.

Through the new Providence ALS Center, Dr. Goslin is creating better stories for many patients. The center is a cooperative arrangement between

Providence Brain Institute, the ALS Association of Oregon and Southwest Washington, and The Oregon Clinic.

This is the first clinic of its kind in Oregon. Here patients experience a true multidisciplinary environment, a “one-stop shop” where they see multiple specialists during each appointment. Studies show that this model of care can lengthen the life span and improve the quality of life for ALS patients.

At most ALS clinics, patients must make multiple appointments to see all of the specialists. Arranging transportation and getting to numerous appointments takes a harsh physical and emotional toll on ALS patients, who have increasingly limited mobility.

Rotation of Caregivers

On this October day, seven patients have clinic appointments at Providence ALS Center. Each will spend up to three hours receiving care.

Once the patient is settled comfortably into an exam room, the sequence begins. Ten specialists – Dr. Goslin, a pulmonologist, a physical therapist, a speech-language pathologist, a social worker, a nurse, a respiratory therapist, an occupational therapist, a dietitian and an augmentative communication specialist – take turns rotating through the room.

Each one talks with the patient, evaluates his or her condition and makes careful notes. Some prescribe exercises or other interventions. All give practical tips to offset the effects of ALS and maximize the patient’s capabilities.

The sense of sharing is palpable. Over weeks and months of ongoing appointments, therapists and patients become friends. They chat amiably about grandchildren, speak honestly about fears and, with respect and dignity, discuss topics that others might consider too personal to voice.

“We have the experience and resources to help patients adapt to their changing abilities without losing their dignity. With information, patients can make informed choices about therapies. That gives them a sense of control over their situation.”

KIMBERLY GOSLIN, M.D., Ph.D.

“This team is the power of our program,” declares Dr. Goslin. At the end of every clinic day, the team members meet to share their notes regarding each patient. “This meeting is vital,” says Dr. Goslin. “As we meet with the patient, we’re all learning something more about the patient. We each get a different piece to the puzzle. At the team meeting, we put all of our pieces together. Getting the perspective of each team member allows us to view the patient as a whole person.”

The team then writes a letter to each patient, reporting their findings in layman’s terms and restating the recommendations they gave the patient during clinic.

“Depending on the patient’s stage of disease, he may not need a dietitian or a speech-language pathologist today,” says Dr. Goslin. “At some point in the future, however, he will need that specialist. By having the patient meet with each specialist at every appointment, we can get a baseline assessment. We monitor his condition from that point forward and initiate therapies as soon as they are indicated. This preserves the patient’s health as long as possible.” >>>



Helping patients take positive action keeps Dr. Kimberly Goslin (top) going. Unlike doctors who can cure disease with medicines or surgery, Dr. Goslin faces each day knowing she can’t cure her patients. Instead, she and her team of experts arm patients with options and resources, such as the augmentative communication device used by clinic patient Carol and social worker Lance Christian (above) as they discuss legal and counseling issues.



Well-orchestrated clinic appointments are vital to both the Providence ALS team and their patients. Regular interaction with each team member gives patients such as John (above) and Colin (below) the benefit of frequent evaluation and timely interventions. Team members benefit from the opportunity to monitor patients' abilities closely and to develop proactive care plans in concert with other team members.



A Glimpse Inside

Among the appointments on this late fall day are Carol, John and Colin.

Carol, 58, bubbles with good cheer. Her sparkling eyes and quick smile belie the challenges she's facing.

Carol's first symptom – a raspy voice – developed a couple of years ago, coincidentally following dental surgery. When the throat irritation didn't improve, she saw numerous physicians before being diagnosed with ALS in February 2005.

It's only been eight months since the initial diagnosis. Carol can no longer speak well and has problems swallowing. Therapists at Providence ALS Center have helped her get an augmentative communication device. Carol now "talks" by typing words into a small device called a LightWRITER, which vocalizes words as she keys them in.

During today's appointment, the social worker asks Carol about her legal documentation: Does she have an advance directive? Has she completed a health care power of attorney? Do she and her husband have any insurance questions?

John is a new patient at the clinic today. Diagnosed seven months ago at age 60, John is having a hard time controlling the muscles in his arms and legs.

Today he's openly frustrated, and who wouldn't be? At 6 feet 2 inches and 240 pounds, John is a big man, used to hard work and being independent. Already that is changing. His sister drove him to the clinic, completes paperwork for him, and stays with him during the appointments to help him remember all that he will learn today.

The former refrigerator technician can't stand without locking his knees and holding on to something. Dr. Goslin gauges the strength of John's grip, then asks about his appetite and his ability to accomplish activities of daily living that

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COLIN, ALS CLINIC PATIENT

he used to take for granted. With his input, she outlines a plan to help him live as independently as possible.

“We treat only ALS patients here. We have the experience and resources to help patients adapt to their changing abilities without losing their dignity,” says Dr. Goslin. “With information, patients can make informed choices about therapies. That gives them a sense of control over their situation.”

Colin, 54, is a man of quick intellect. Without actually speaking a word, he holds a spirited conversation with the respiratory therapist using EZ Keys, a device similar to a LightWRITER. Often the therapist asks only half a question before Colin types his reply. Questions flow freely between therapist and patient.

The president of Island Joe's, a Caribbean restaurant in downtown Portland, Colin developed ALS symptoms two years ago. He now has great difficulty talking and swallowing – ironic for a man who owns a restaurant and loves talking to people. He still, however, has good control of the muscles in his arms and legs.

Today the therapist recommends some breathing exercises to strengthen Colin's lungs and throat muscles.

“I was reluctant to go to the clinic at

first,” says Colin. “I was very happy with my first neurologist. After one visit, I was completely won over. Dr. Goslin and the staff are warm, cheerful and compassionate people who truly want to help me maximize the quality of my life, without dwelling on how catastrophic this all is. Their partnership with the ALS Association really equips them with a tremendous array of resources.”

“We emphasize what patients can do,” states Dr. Goslin. “It’s the difference between seeing a wheelchair as something to which you are confined and seeing a wheelchair as the tool that gives you freedom to move about.”

Carol, John and Colin all schedule their next appointments before leaving the clinic today. Between now and then, they know that Dr. Goslin and her team will be standing by to talk, to encourage and to help each of them in any way possible.

For patients in advanced stages of ALS, Dr. Goslin even makes house calls. Day or night, the doctor often can be found at the bedside of a dying patient.

Knowing that none of her patients

will “live happily ever after,” how does Dr. Goslin find the emotional strength to keep going? How does her team face another clinic day filled with patients struggling against impending paralysis?

“We are very focused on the positive,” Dr. Goslin says. “The worst part in all of this – the part I hate the most – is telling someone for the first time that he or she has ALS. After that, it’s all about the positive. We focus on making things better. We minimize suffering. We think proactively. With the help of the local ALS Association, we arm our patients with resources. We help them maximize their health and continue doing what they can as long as they can.”

And right there, Dr. Goslin and her team succeed every day in creating better stories. ■

During a medical crisis in December, John – aware of his treatment options – chose not to receive invasive therapy. He died at home on Dec. 11, surrounded by his wife, family and close friends.



Facts about ALS

- Nearly 30,000 Americans and 455 Oregonians have ALS. On average, 15 new patients are diagnosed nationwide every day.
- ALS usually strikes people in their mid-50s.
- Men are slightly more likely than women to develop ALS.
- ALS is not contagious.
- Ninety to 95 percent of cases occur spontaneously in previously healthy adults. The remaining cases result from heredity.
- Symptoms may include:
 - Weakness in muscles of the hands, arms or legs or in muscles used for speech, swallowing or breathing
 - Twitching and cramping of muscles, especially in the hands and feet
 - Impaired use of arms or legs
 - Thick speech and difficulty projecting the voice

Advances in the treatment of ALS are being made. Many patients are living longer and enjoying better quality of life. Physicians can now diagnose ALS in earlier stages so patients can start therapy before muscles waste away to a critical point. Researchers are developing new medications to better control symptoms and studying genetics in an effort to prevent some types of ALS.

ALS patient used business skills to build local support

Steve White was a gifted manager in the business world, dynamic and well-liked. His forte was his ability to inspire people.

Diagnosed with ALS 10 years ago, White turned his skills to health care. He became a driving force behind the formation of the Oregon and Southwest Washington Chapter of the ALS Association and served on the chapter’s board of directors.

Paralyzed and homebound for the last two years, White used an external breathing support system and communicated via a laser-beam-activated computer, which he controlled with subtle head movements. These limitations did not stop him. One of his dreams was a multidisciplinary ALS specialty clinic in Portland. Although White died unexpectedly on Dec. 8, 2005, from pulmonary complications, Providence ALS Center bears testimony to Steve’s vision and energy.

“Steve had an incredible vision for making resources available to patients and for educating people about this disease,” says Lance Christian, M.S.W., services director for the chapter and social worker at Providence ALS Center (below with White at his home in November 2005).

