

Spreading the word

Written by Deb Egenberger

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Boden uses spokesperson title to inform, counsel about ALS.

Leaning against the counter in front of the kitchen sink with a carrot in one hand and a peeler in the other, a new reality hits.

A simple task such as preparing carrots for supper will be added to the growing list of no-longer-possible chores.

Nearly every day, Lellus Boden learns something new about the disease she has lived with for almost four years.

Maybe it's a household job she has lost the strength to do at the rural home she shares with her husband Edgar in the heart of Wild Horse Valley north of Brady.

It might be results of a new study on patients with amyotrophic lateral sclerosis (ALS). Or it could even be the name of the Nebraskan with the most recent diagnosis.

"I have learned so much," Boden says, "and I still feel like I'm in the dark."

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ALS SPOKESPERSON

Lellus Boden of rural Brady in the Nebraska
Muscular Dystrophy's 2010 spokesperson for
amyotrophic lateral sclerosis, ALS.
Anyone wishing to learn more about the
disease or join a statewide telephone support
group may contact her at 308-584-3520.

After a year and a half of intense medical tests and specialist consultations, Boden was diagnosed with ALS—a degenerative neurological disease also known as Lou Gehrig's disease—in August 2006 at age 72.

Her doctor was straight forward with the diagnosis, telling her ALS is a fatal disease with no cure.

"I basically received a death sentence," she said, "but I instantly knew it all had a purpose."

Boden has since participated in several research projects in Lincoln through the University of Nebraska, including an experimental drug study.

During her most recent part in UNL research, Boden ate Cheerios while a room full of cameras focused on her face, jaw and neck.

Boden has also taken part in mental testing to gauge the effects of ALS on the brain. New research is indicating the disease may contribute to dementia.

"It's been a privilege," she said of being included in the research. "I see it as a wonderful opportunity to help others."

WHAT IS LOU GEHRIG'S DISEASE?

Amyotrophic lateral sclerosis (ALS) is a motor neuron disease which commonly strikes people between the ages of 40 and 70. Approximately 5,000 people in the United States are diagnosed with ALS each year with as many as 30,000 having the disease at any given time. Lou Gehrig first brought national and international attention to the disease in 1939 when he abruptly retired from baseball after being diagnosed with ALS. The average life expectancy is between two and five years after diagnosis. Symptoms may include: muscle weakness in the hands, arms, legs or the muscles of speech, swallowing or breathing; twitching and cramping of muscles, especially those in the hands and feet; impairment of the use of the arms and legs; "thick speech" and difficulty in projecting the voice based on the degree of disease; and emaciation, shortness of breath, difficulty in breathing and swallowing. Source: www.alsa.org

Encouraging family and friends has been a way of life for Boden forever, whether that meant

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baking a cake for a funeral reception or sending a card congratulating a birthday.

But when the Nebraska office of the Muscular Dystrophy Association asked Boden to help even more people by being the ALS spokesperson for 2010, she was hesitant.

“I live way out here in the boonies,” she said. “I didn’t know how I could help.”

In her new role, though, Boden has provided one more personal contact for new ALS patients.

“Last week I talked to a man from Kearney who is waiting for a final diagnosis,” she said. “And not long ago I was put in touch with a woman from Grand Island who didn’t want to talk to anyone else about it. She didn’t want to face it.”

What does Boden say over the phone to ease the fears?

“It’s not what I say but what I hear,” she said. “I share my faith and I ask about their support but mostly I just listen to their fears and let them express their feelings.”

Boden also participates in conference calls that allow for an exchange of information as well as support for fellow patients.

“This is one way that I can speak for others with ALS who cannot speak for themselves,” she said.

Spreading information about the disease is one of Boden’s latest missions.

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“The diagnosis is difficult,” she said. “If people recognize early symptoms, it might lead to earlier diagnosis and greatly contribute to earlier health care and quality of later life.”

The first symptoms may be muscle weakness or stiffness which are often attributed to something else.

As ALS progresses, muscle cells gradually disintegrate until the ALS patient eventually becomes paralyzed with death often resulting from respiratory complications.

“We’re all dying every day,” Boden said. “It’s just that not everyone has been given a timeline. I don’t look at my timeline as a limit. I choose to look at it more as a challenge to see what I can do with what I’ve got left.”

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