Barbara and Bill Hutchinson, Travelers Extraordinaire by Helen Whitworth Summer, 2007

Recently, the Georgia Chapter Alzheimer's Association put Barbara and Bill Hutchinson on the cover of the spring edition of their glossy newsletter. It told about the couple's remarkable trip from Alaska to Florida. Barbara and Bill are in Fort Meyers, Florida now, staying with their daughter and aren't planning to travel, at least until time for the Volleyball Tournament that another daughter is planning for Sacramento in August. Right now, they are looking forward to a family reunion at Fort Meyers, with all five daughters, a couple of sons-in-law and all 15 grandchildren, coming from all over the country. (Later: Barbara did attend the tournament, but Bill was too weak to go. He passed away soon afterward. HW)

Barbara and Bill's trek started when, after several years of symptoms and at least one other diagnosis, Bill was finally diagnosed with LBD in 2005. At first, Barbara, a nurse, tried to work and care for Bill, but she found the two jobs incompatible. The day after she retired, Barbara said God told her, "You are free. You can tell the world about LBD." And before long, she had Bill packed into their motor home. "God planned ahead," Barbara explained. "I had the motor home when I was a traveling nurse before we moved to Alaska in 2005."

They started in Valdez, Alaska, motoring to Anchorage, where a daughter lives. Then they took a ferry to Seattle, Washington, and started motoring again. Traveling with Bill is different than regular travel because he can only do about 200 miles a day. But when they got wherever they were going, Bill was fine because he was "home." They slept in the same bed every night and had their own belongings around them. "We'd never have been able to do it if we'd tried to do it with motels," Barbara says. Usually, they stayed in one place at least 2 weeks before moving on, sometimes a month or more if there was family to visit or if Barbara could get some good "gigs."

Yes, gigs. Well, Barbara calls them "talks," but from Valdez to Fort Meyer, for almost a year, Barbara and Bill did a show about LBD for anyone who will have them – Rotary Clubs, churches, Elks Clubs, etc. It wasn't unusual for these talks to be met with stunned silence. It was a two-person show. As Barbara told about how dynamic Bill used to be, Bill's quiet presence was a physical example of how LBD changed a person. Barbara and Bill did 2-6 talks a week for most of their trip and gave out over 4000 LBDA brochures. Besides the Alzheimer's Association article, Barbara was interviews by several newspapers and radio stations and even appeared on a local TV show.

But their trip wasn't all work. One of Barbara's fondest memories was in Nevada when they were visiting relatives. She and Bill went with some of Barbara's family to play golf on a little course nearby. Barbara's uncle had recently had a stroke and wasn't doing so well himself, but he took over Bill's care, taking his hand and leading him around the course.

High on Barbara's list of memories were her visits with other LBD caregivers across the nation. She explained, "There was always a closeness right off. We could share things with each other that one can't share with even close friends, because we understood each other." She found many of the caregivers were lonely and isolated because they were trying to make it on their own.

One of the questions that usually came up at her talks was "How do I help my friend who is a caregiver?" Often the questioner would say, "I've tried to help, but she won't let me." "Yes," Barbara would answer, "I used to think I had to do it all myself too." That changed for Barbara when, during their travels, a woman she met appeared at her door with a whole meal for her and Bill. That's when she learned how wonderful it felt to be the caree instead of the carer for a change. "It gave me a lift and helped me continue on with an often difficult task," she'd tell her audience. "This person didn't ask; she just did. And that's what you have to do. Go to your friend's house and do whatever needs doing, like washing the dishes or vacuuming the floors. Bring someone she trusts to watch over her loved one and take her out to lunch. But don't ask, 'What can I do?' because we don't know. And don't say, 'Just call me if you need help.' We won't call."

Barbara says now, "I've learned to accept help. I know it is important to my wellbeing and therefore to Bill's." When she talks to other caregivers, she tells them, "We don't know how to ask for help. This is really hard for us to do, but we have to realize that we need help to be able to do our job well. And I've learned that people want to help. They just don't know how and instead of turning them off, or ignoring them, we need to teach them."

"Be specific," she says, "Tell them you'd love to have an hour to run errands. Tell them it would be wonderful if, just once, you didn't have to get dinner or wash that mountain of dirty clothes or worry about the yard getting mowed. It's OK to accept help, even to ask for help. It doesn't mean we are failures at our job, it means we recognize that help from others can give us that lift in spirits that makes us better caregivers."

For more information, you can contact Barbara at bbhutch44@hotmail.com or her daughter, Kristine Spencer, at klaramid@aol.com.