

Messages from Barbara Dickinson

Excerpts from Barbara Dickinson's messages

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"My name is Barbara Dickinson. I'm the trustee of the Rhode Island Chapter of The ALS Association and also a national trustee of The ALS Association. I got involved with ALS because my husband was diagnosed nine years ago with the disease. We made some decisions in the course of his disease that has allowed him to have a quality of life that I would hope more patients with ALS would be able to achieve, and that's what I want to talk to you about today.



"I think there are really three things that get wound up into one. The first is that being a caregiver for a disease like ALS is completely and totally exhausting, both physically and emotionally.

"The next challenge is that caring for someone with ALS is financially extremely draining.

"And third is when you begin to realize that you've got to get some help. Help is extremely expensive. HMOs and other insurance companies believe that family members can care for victims of ALS in their home without any help, outside help. But I can tell you that it can't be done for any long period of time."

On getting assistance with care:

"The HMO told us that we would not be allowed to take my husband home, that he would have to go into an institution, a critical care nursing home. And we sat down, all of us in a family conference, and also with my husband's doctor, and just decided that this was unacceptable and that we were going to do what we could to bring him home and to continue to care for him in our house. But we understood, because someone who is on a respirator needs 24-hour constant care, that we would have to have help.

"We decided to challenge the HMO, and we did this by hiring an attorney who was a specialist in medical insurance. The attorney, in reading the insurance policy fine print, found a clause that said that the insurance policy had to provide comparable care, that they could not downgrade my husband, or any of their patients, from one level of care to another. And what that meant was that they would have to provide something that was the same as or equal to a nursing home.

"So what we asked for was for them to give to us the amount of money they would have paid a nursing home to care for my husband and allow us to hire private care to care for him at home.

"Well, we did have a series of very sometimes acrimonious meetings with the insurance company. We just kept pleading our case. We were lucky in that my husband was fully employed, and it was to his benefit that he continued to work, which he would not have been able to do in a nursing home. But we also used the power of the press, and we said we would present a very unflattering picture of how the HMO was responding. I pointed out to the HMO that when a person buys life insurance the buyer is gambling that they will get sick, and that the insurance company is gambling that you won't get sick. And in our case the insurance company lost and then they had to pay their debt. And they lost the gamble, so pay up.

"Well, the result was that my husband has lived at home for the last six-and-a-half years. He continues to be fully employed. He's continued to write his column, less and less in the last few months as his illness has progressed, but for about five years he entered a wonderful plateau. It's not a place where anyone would really like to be since he couldn't talk, couldn't eat, couldn't breathe, couldn't move anything except his eyes

and his mouth enough to smile. But he did see children married. He did see two grandchildren born. And we've continued to have him as a part of our family life during all this time, and that has been very important to all of us.



"The ALS Association has an annual advocacy day in which numbers of chapters go to Capitol Hill to talk to senators and representatives about the disease. Local people can contact their congressmen and congresswomen and ask them to become aware of how difficult it is for families who are facing devastating diseases to get the kind of in-home care they need.

"Don't neglect the power of your local media if you want to make a case for what you should be able to have. Go to the television station. Go to the newspaper. Go to talk radio and talk about what your needs

are, why they are important and what you think the good help would be for you.

"Join with other people in your situation to form advocacy groups who will figure out ways to put the pressure on local institutions who might be able to provide some kind of help. Your local chapter of The ALS Association or the national ALS Association may be able to help you with advocacy efforts.

"When you talk to an insurance company, always go to the highest official you can reach with your problems. They're not as likely to say "no" automatically. And above all, don't give up."

On the impact of ALS on the spouse/caregiver:

"I can't remember that anything has ever frightened me more than the prospect of living with this disease. I think my first reaction, and I know my husband's, was just cold fear. It would wake me up in the night. It would be the first thing I would think of in the morning. I had no idea what we were going to do, how we were going to handle it. And with that fear was a grief so terrible that I used to have to stop my car by the side of the road on the way home from work so that I could cry and then try to keep on going.

"Well, I realized that I was also very angry. What made me realize I was angry was that I began to drive like a maniac. I couldn't stand to have anybody in the passing lane who wasn't going as fast as I thought he or she should be. I couldn't stand for anyone to do something stupid. I had no tolerance or patience for anything that was going on. I was also terribly worried about how I was going to handle this and where the money was going to come from how we were going to get through it as a family, what the future was going to hold, how would we handle each new day as it came up. And there were terrific feelings of isolation. I stopped being who I thought I had been, and I became this other person, this caregiver. I was no longer really a wife. I was no longer really a mother. I just had this other identity where I was taking care of someone who was getting worse and worse every day.

"As far as physical ailments go, I had backaches, I had a lot of tension, which resulted in headaches and a lot of other muscle aches. My blood pressure went up. I lost quite a bit of weight in the beginning. And my boys, who were now working at least as hard as I was physically, had back problems and muscle aches.

"I dreamed regularly that I had ALS. I still do, although maybe a little less frequently. I would be trying to walk somewhere, and I couldn't lift my legs. I would be trying to climb a flight of stairs, and I'd have to reach down with my hands and lift one leg after the other to go up a flight of stairs. I couldn't run in my dreams. And I would wake up from these dreams because somewhere in the last minutes of the dream I would think, "but we can't both have ALS." So I'd wake up in the dream, thinking, "Thank God it was only a dream," but on the other hand, that's what he's got. This is what he's going through."

"And I also used to dream, and I still do once in awhile, that I had this huge mess to clear up. I had a lot of things I had to pack. They all had to be put in boxes or suitcases, and I had to get this all done so that I could catch some kind of transportation, a train or a plane or something, and I could never get it done on time. No matter how hard I cleaned or how fast I tried to control it, the mess just spread and spread and got bigger and bigger. So inevitably I missed whatever form of transportation it was.

"Well, on the advice of our wonderful family physician, I saw a psychiatrist and went into counseling with the psychiatrist, and so did my husband and my children. Finally I took some antidepressants, which made a big difference to me because they allowed me to sort out my concerns and prioritize what was important and what wasn't important.



"I also had wonderful advice from a dear friend, who said two things to me. He said, first of all, you're going to find out who your real friends are. People that you think you could count on are going to disappear, and other people are going to come from nowhere and help you out with this. And then he said, lots and lots of people are going to be taking care of your husband but nobody is going to be taking care of you. So you're going to have to find out a way to take care of yourself.

"And I began to do something I'd never done before in my life, which is to go have my nails done every week, which was an opportunity to get in a kind of girly environment and let somebody do something for me, and it was an hour and it wasn't very expensive. So it was something I could fit in. And it did help.

"In the beginning, I absolutely hated what this disease did to our lives. I hated every modification that we had to make. I hated having ramps for wheelchairs. I hated having handicapped lifts in bathrooms. I hated having equipment all over the house. I hated that the kitchen became a pharmacy because I began to feel I was losing the only haven I had, which was my house. But now, I don't know what it would be like to have a house that was not a hospital. One of our rooms is a hospital room now with a hospital bed. There are ramps all over the house. There is equipment everywhere. We're used to it now. The difficulty is there's no privacy. I don't have anywhere to go in my house now to be just sort of a normal person. I can't come downstairs in a slip to get a glass of orange juice or any of those things that people normally do in their own houses because I'm never alone in my house. In fact, there can be ten or twelve people in and out of the house in a week, bringing in supplies and doing various things that need to be done. So it's made me retreat to a certain extent into my bedroom as a sanctuary.

"Of course, I'd really like to find a cure, or at the very least a management for ALS. And I'd like to see that insurance providers would come to recognize the burdens that they impose on caregivers, not just for people with ALS but for people with Alzheimer's, for people with cerebral palsy, for people with all the other diseases for which 24-hour care is essential to the well-being of the patient. I'd like them to realize what kind of burdens their policies place on caregivers and on the patient, and I'd like to see them address how they can become more humane and more caring.

"Lobby your representatives and your senators and try to get them to understand that we have to change the healthcare system in this country and that the healthcare insurers have to change their policies so it becomes a better place to live in America when you're coping with an illness."