

**Amyotrophic Lateral Sclerosis:
A Comprehensive Guide to Management,
Norris, F.H. Mitsumoto. H. (Eds.)
Demos Publications, Inc., New York, 1992.
Chapter 14 Successful Home Care
Experienced in May 1991**

Experiences in Japan

Ben Cohen is a 46-year-old American citizen who has been living in Japan since 1974. He is a distinguished potter of Echizen pottery and quite renowned for his work in that country. When stricken with ALS in the summer of 1989, little did he know that his two- to five-year life expectancy could be shortened.

As his body deteriorated physically, Ben waited for bulbar dysfunction to strike. Through his own research, he felt that bulbar dysfunction would progress before the onset of any pulmonary problems. However, sudden respiratory distress and CO² narcosis left him with a life-or-death decision. Ben chose life.

Although Ben is married to a Japanese woman, which qualifies him for health care benefits, there are no home health care agencies in Japan. Patients on ventilators there are usually placed in hospitals. Those patients who can no longer make their needs known are fed and kept clothed and dry, but there may be little quality to their lives. For those Japanese who can afford them, private nurses in the home are available but extremely costly, and family and fellow nurses must train them.

The remote fishing village in which Ben lives is limited in medical personnel. The villagers of Kadanji gathered together and made a commitment to bring Ben home and to learn to care for him. A committee was formed of friends, some professionals, and three local doctors to organize the training of local rice farmers, fishermen, and fellow potters.

An ALS consultant was hired by a group of Ben's friends in Los Angeles who had started their own fund raising. This nurse spent three weeks in Kadanji, training anyone who walked through the door. A videotape was produced and translated into Japanese for Ben's caregivers. The video demonstrated the vital services required to sustain Ben's life on a ventilator system. A "how to" video of his breathing treatment, exercise routine, turning and positioning, transferring, and maintenance of his machinery was observed. Ben turned out to be the best student. He was taught to know his body and to listen to it. Ben needed to be the primary teacher of his caregivers, and this task required great patience, trust, and courage. As his caregivers would do return demonstrations, he learned to compliment and encourage the novices as well as tactfully advise the professionals. A daily plan of care was written describing his hour-by-hour routine. ALS patients usually prefer routine and consistency in order to maintain that control in their life. Ben is still alive today and continues to work designing his pottery. Although he can move only his eyes and mouth, he designs his artwork on the computer and employs his wife, Reko, to serve as his hands. His caregivers act as his team when the pottery goes for firing twice a year. Since stricken with ALS in 1989, Ben has displayed his latest artwork in Tokyo galleries three times.

What was done in Japan is also what the ALS consultant does in the United States or, for that matter, anywhere. After consulting with the physician, other team members, the patient, and family, he or she writes a comprehensive detailed plan of care. An hour-by-hour, step-by-step plan is established by reading the care plan, observing the care, and reviewing it on a VCR, which can also be used for demonstrations.

Finding the right personnel to care for an ALS patient is not an easy task. The nurse who needs to see that his or her care is helping the patient get better may become stressed working with ALS patients who are in continual decline. Nurses should be carefully screened for competency and personality. A good knowledge of nursing and how to respond to system breakdown is essential. Nurses and caregivers should be encouraged to work with the patient in

determining what nonprescription actions may remedy a given situation before the physician is contacted. Personality also plays a large part "in the screening of the nurse who will be the caregiver. Knowing as much about the patient's personality and determining what his or her particular likes and dislikes are enables the consultant to select the best nurse to work well with the patient. There are no stereotypes. Young patients do not necessarily want young nurses. Sometimes they want to be mothered by someone older. Older patients may not want a nurse of their age, but perhaps someone younger.

One thing they all want however is the nurse or caregiver who makes them feel secure and hopeful. Hopeful is very often a difficult word for the ALS patient to accept. The caregiver should not destroy the patient's hope-nor is it fair to offer false hope. The best course the caregiver can take is to assist the patient to achieve as much control of life as possible through encouragement and the promotion of decision-making skills. Even if patients can only blink their eyes in a yes- no response, simple things that they decide will give them this control-decisions about what clothes to wear, what to prepare for supper, what bills to pay. A routine should be maintained for as long as possible, be it church, bingo, PTA, baseball, and so on.

The best advice that can be shared with all caregivers for the ALS patient is to facilitate patient dignity. This is one of the few things that ALS should not be allowed to take away. Remember that the patients want to be treated, as they were when they were healthy and productive members of society. Their productivity as an ALS patient is only limited by their own desire and determination.