

# Evaluating and Caring for the Caregiver

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There is no doubt that ALS presents enormous challenges for those whom it strikes. But it is also apparent to those with ALS and those of us who care for such individuals that ALS affects not only the person with the condition, but also their caregivers. Who are these caregivers? Usually they are family, most commonly a spouse, but often a child, parent, or other relative or close friend. A survey of 98 persons with ALS found that their primary caregivers spent a median of 11 hours per day in caregiving (1). For 52 ALS patients on mechanical ventilators, the burden on the caregiver was even higher, averaging 14.4 hours of care per day and 2.4 awakenings per night (1). Such an intensive experience can take a toll on caregivers. Nearly half of ALS caregivers reported feeling psychologically unwell, and 42% felt physically unwell (2). Over time, the psychological well-being of most ALS caregivers worsens (3,4).

Yet, a visit to ALS clinic by the patient and caregiver is understandably filled with assessments of, and recommendations for, the person with ALS. The importance of the caregiver is certainly recognized, because without a caregiver there would be no (or certainly less) care for the person with ALS. But, as we have seen caregivers suffer physically and psychologically, many of us have asked whether we are doing enough to ensure the caregiver's health. What can be done to help? How can we help to care for the caregiver?

For her doctoral dissertation in psychology, Virginia Murphy, a former student of Stephanie Felgoise, PhD, and now a PhD herself, studied 75 caregivers in our ALS clinic to determine whether problem solving might be one factor involved in caregiver mental health and quality of life. She looked specifically at "social problem solving," which involves several parts: 1) problem orientation, in which a positive problem orientation indicates a tendency to view problems as challenges or opportunities rather than threats; 2) behavioral response styles, or how one tries to solve problems, whether in a rational way or impulsive/careless way, or not at all; 3) problem solving skills, including defining the problem, generating choices, making decisions, implementing them, and assessing them. She found that better problem solving abilities predicted less caregiver psychological distress and better caregiver quality of life. In contrast, there was no relationship between the amount of care provided and caregiver psychological distress or quality of life. Thus, caregivers providing the most care were not necessarily those with the greatest psychological distress or lowest quality of life. Rather, caregivers with the best overall QOL and the lowest overall psychological morbidity were those with a positive problem orientation (a tendency to view problems as opportunities rather than threats) and those whose behavioral response style was rational rather than impulsive, careless, or characterized by avoidance.

As ALS team members, we must be aware that simply providing additional personnel to help reduce care hours for the primary caregiver is not the whole solution to caring for the caregiver. This knowledge presents us with opportunities because problem solving skills can be and have been successfully taught to caregivers of individuals with cancer, resulting in improved quality of life and psychological health for the caregiver. Problem solving skills are important, but only one part of the overall approach needed to care for the caregiver. We are currently using a system called Evidence-Based Practice to identify how best to accomplish this. We hope to use this to develop a holistic approach to evaluating the caregiver and identifying and implementing the means to reduce caregiver burden and improve caregiver quality of life. We believe this should be an important part of the services we provide in ALS Centers of Excellence.

### References

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