



Peer Professional Workgroup on Amyotrophic Lateral Sclerosis (ALS)

Bringing medical leaders together for idea generation

SUMMARY

The Amyotrophic Lateral Sclerosis (ALS) Workgroup of the Robert Wood Johnson Foundation's (RWJF) *Promoting Excellence in End-of-Life Care* national program sought "to catalyze rapid change, resulting in improvement in the care of patients dying of ALS and their families." The ALS Workgroup was one of eight peer professional workgroups formed by national program office staff to bring medical leaders together to generate new ideas for their fields.

ALS, also known as Lou Gehrig's disease, is a progressive neurodegenerative disease that affects about 4,600 Americans each year. There is no cure for ALS, which typically leads to death three to five years after symptoms begin.

As the disease progresses, most people suffering from ALS and their families must make decisions about whether and when to forgo active treatment or life-sustaining care. Most ultimately decline aggressive treatment, making palliative care essential.

The Project

Hiroshi Mitsumoto, MD, DMedSc, director of the [Eleanor and Lou Gehrig MDA/ALS Research Center at Columbia University](#), chaired the workgroup. The national program office contracted with the [ALS Association](#) to provide administrative support. The group of 22 clinicians and social workers met in person twice and via telephone conference calls monthly between June 1999 and November 2001.

Working in subcommittees, workgroup members addressed issues related to the end of life in ALS within the following domains:

- General psychosocial care
- Bereavement
- Spirituality
- Quality of life
- Caregiver issues
- Communication skills
- Ethics
- Decision-making

- Symptom management
- Access to care
- Costs of care
- Knowledge/education

In each domain, members identified the current state of knowledge, determined markers of ideal care, recommended ways to close the gap between current and ideal care and identified tools for clinicians and other staff.

Key Results

In 2002, the ALS Workgroup released its report, *Completing the Continuum of ALS Care: A Consensus Document*. The report offered practice, research and policy recommendations in each domain, and included extensive appendices containing tools and resources. See the Project Sites Bibliography in the *Promoting Excellence in End-of-Life Care Program Results Report*.

Key Recommendations

Examples of recommendations in the report:

- Clinicians should use the following triggers as criteria in deciding to initiate discussions with patients about end-of-life care:
 - The patient or family asks for information or help in addressing the disease or its symptoms.
 - Severe psychological, social or spiritual distress or suffering.
 - Pain requiring high dosages of analgesic medications.
 - Need for a feeding tube.
 - Difficulty breathing or symptoms of hypoventilation.
 - Loss of function in two body regions, such as the arms, legs or facial muscles used for speech or swallowing.
- Because ALS progresses over time, family members often assume large burdens in caring for people with ALS. Therefore:
 - Clinicians should interview caregivers to identify concerns that require attention.
 - Researchers should develop an instrument to measure caregiver burden. They should then study whether that burden can be reduced by offering services to caregivers before they become overburdened with worry and responsibility.
 - Policy-makers should improve financial and insurance coverage for home-based care.

- Decisions about forgoing or withdrawing life-sustaining interventions often involve considering beliefs that patients or families may not have previously explored.

Therefore:

- Doctors or others working with families should identify and monitor conflicting issues associated with end-of-life care, including conflicts within families and between patients, families and health care providers.
- Researchers should study the effects of end-of-life decisions on families and caregivers and on the overall quality of life during the terminal phase of ALS.

Funding

RWJF supported the workgroups through a \$847,888 grant to the national program office to manage the program.

Prepared by: Mary Nakashian

Reviewed by: Karyn Feiden, Marian Bass and Molly McKaughan

Program Officer: Rosemary Gibson

Project Director: Ira R. Byock
