

ALS Congregational Care Teams: Bridging the Gap

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Objectives

- To learn what an ALS Congregational Care team is
- To learn how such a team can be constructed
- To learn how such a team can positively impact the life of a family living with ALS.

Rationale for an ALS Congregational Care Team

- The Community of faith is the natural setting for non-medical support to be compassionately given and trustingly received
- At the heart of all faith traditions is the desire to offer care, compassion and support

What is an ALS Congregational Care Team?

An intentionally formed group of 3 – 5 volunteers from a patient's community of faith who are committed to coordinating non-medical support to a person with ALS and the person's family

Non-Medical Support

- Providing Meals
- Grocery Shopping
- Laundry
- Transportation
- Lawn Care
- General Errands
- Handicap Additions
- Child Care

An ALS Congregational Care Team

Bridges the gap

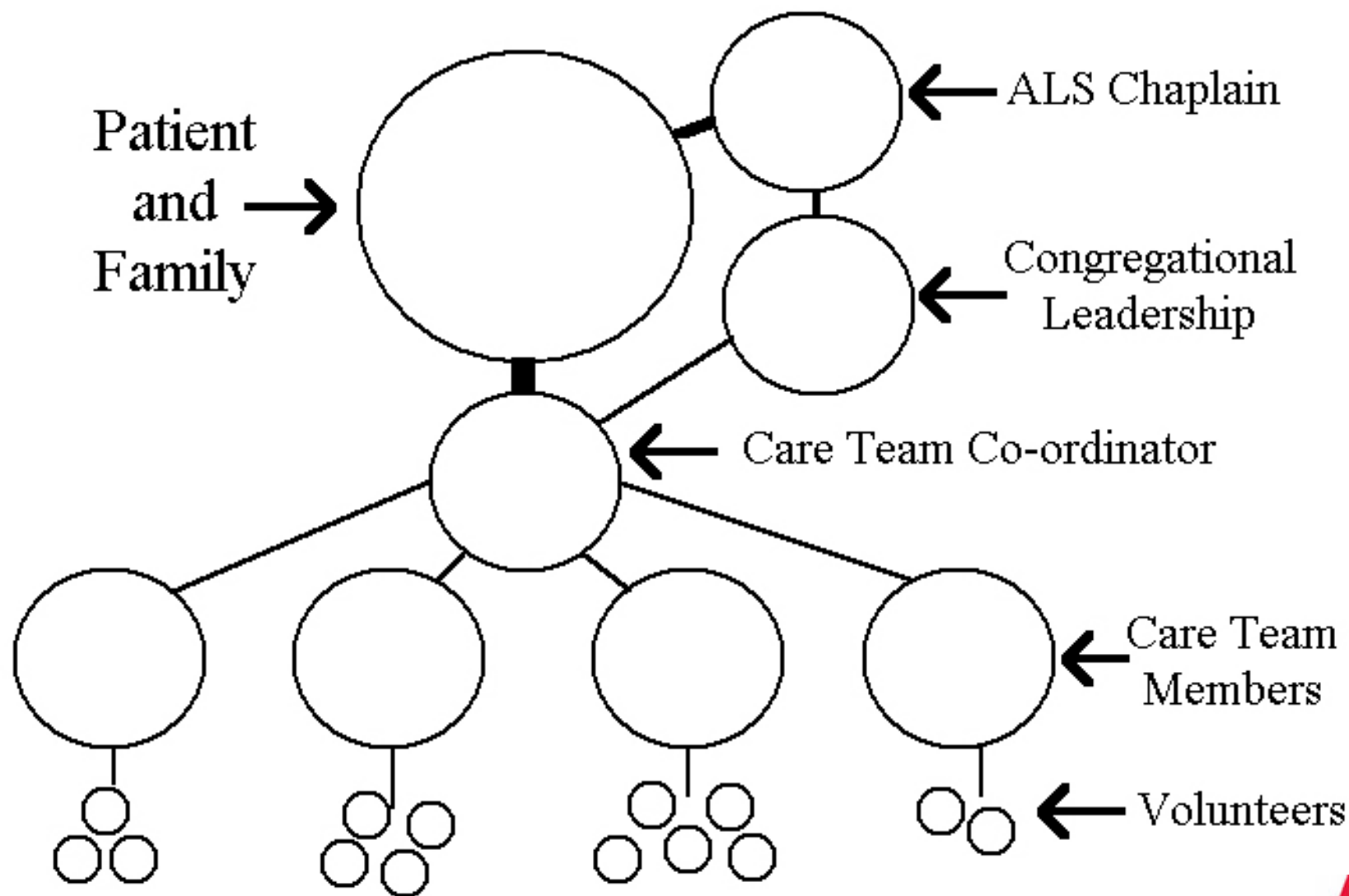
Between the world of medicine and
the world of faith

In a unique model that has not been
employed elsewhere

Composition of an ALS Congregational Care Team

- The person with ALS
- The family of the person with ALS
- ALS chaplain
- Care team coordinator
- Care team members (3-5)
- Lay volunteers

Care Team Model for ALS Patients & Families



Steps to Make an ALS Congregational Care Team Effective

- **Educate** the patient's family and the patient's community of faith
- **Organize** team members
- **Implement** non-medical support

Role of the Chaplain

- **Guide** the formation and implementation of the ALS Congregational Care Team
- **Monitor** the functions of the ALS Congregational Care Team and the needs of the family over time as the disease progresses
- **Serve** as trouble shooter

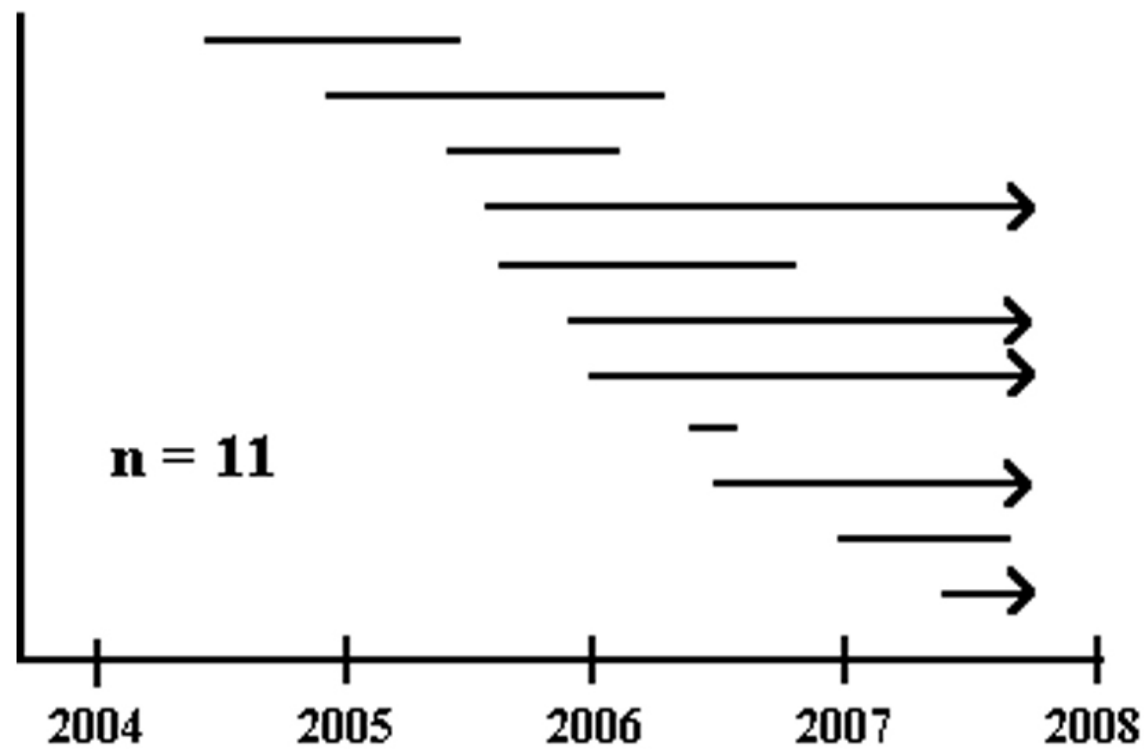
Role of the Family

- **Understand** the concept and guidelines
- **Link** chaplain with congregational liaison
- **Identify** family non-medical support needs
- **Maintain** established guidelines of the ALS Congregational Care Team

Role of the ALS Congregational Care Team

- **Gain** Basic ALS education in the congregational setting
- **Understand and Promote** appropriate support skills unique to ALS
- **Coordinate** non-medical support needs as identified by the family

Congregational Care Teams



Challenges for an ALS Congregational Care Team

- **Adjusting** to changes in support needs as ALS progresses
- **Maintaining** guidelines as ALS depletes patient and families physical, emotional and spiritual energy
- **Respecting** the resources within the congregation during the duration of the illness

Outcomes

This presentation is about 11 care teams; it is difficult to show statistically, with such a small number, that the development of teams such as these improves patient and family satisfaction and quality of life.

However, the responses of patients, families and care teams are encouraging and support its effectiveness.

Outcomes

Family Responses

- Appreciation for a knowledgeable well-guided support system throughout the disease progression
- “The chaplain could say clearly and directly for us what was happening in our lives and what support we needed”
- “You [the chaplain] helped our family to identify our needs and to trust others to be in our home”

Outcomes

ALS Care Team Responses

- “Your [chaplain] educating, guiding and companioning gave us courage when we did not know how to help our hurting friends”
- “You [the chaplain] were able to help our team maintain boundaries and make a difference for this family”
- “This has been such a learning experience. It was good to know that we were offering what the family needed”

Outcomes

ALS Chaplain's Response

- Ten of 11 teams “ran smoothly”
- Keys to success:
 - Education of family and community of faith
 - Communication, communication, communication on a regular basis
 - Flexibility to needed adjustments
 - Maintaining boundaries of commitment

Outcomes

Quality of life in ALS depends on factors other than strength and physical function.

Simmons Z, Bremer BA, Robbins RA, Walsh SM, Fischer S

Neurology 55:388-392, 2000.

Outcomes

In a study of 80 patients with ALS, the single most important factor related to ALS patient's quality of life was their social support. Patients who receive emotional support from their families and friends are more compliant with medical regimens, less likely to be depressed, and less likely to suffer from other adverse health consequences than those that do not receive effective support.

A cross-sectional study on determinants of quality of life in ALS

Chio et al; J Neurosurg Psychiatr 75:1597-1601,
2004:

An ALS Congregational Care Team

- **Provides** a significant source of compassion and support for persons with ALS and their families
- **Fulfills** the mission of the community of faith: offering support and compassion to those in need

“When people are overwhelmed by illness, we must give them physical relief, but it is equally important to encourage the spirit through a constant show of love and compassion. It is shameful how often we fail to see that what people desperately require is human affection. Deprived of human warmth and a sense of value, other forms of treatment prove less effective. Real care of the sick does not begin with costly procedures, but with the simple gifts of affection, love and concern.”

- The Dalai Lama