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.

His Holiness, The Dalai Lama

Time for Listening and Caring

The perpetually debilitating effects of amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s disease, greatly impacts both patients and their families. This terminal disease produces numerous physical manifestations, e.g., decreasing mobility, difficulty eating, loss of energy and eventual paralysis. Activities of daily living (ADLs) become increasingly difficult for the patient, which has a rippling effect on family members, making everyday existence difficult for the whole family. A natural source of nonmedical support is the faith community. Whatever the denomination or tradition, such action fulfills the mission to “carry one another’s burdens” in time of need.

The care team model utilizes a congregational care team (CCT), which is an intentionally formed group of three to five volunteers who are committed to coordinating nonmedical support to a family living with a challenging illness—whether chronic or terminal.

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This model assures that all volunteers receive education appropriate to a particular illness and agree to serve under the direction of a coordinator and to follow specific guidelines.

In the ALS model, developed at the Milton S. Hershey Medical Center (MSHMC), Hershey, PA, the chaplain works closely with the designated CCT coordinator as the disease progresses and support needs change. Thus a significant bridge is created to fill the gap between the world of medicine and the place of home and community life. The chaplain serves with one foot in each world.

Throughout the process, the chaplain advocates for the patient/family’s nonmedical support needs while respecting the resources and present life of the congregation. This balance helps those providing support as well as those receiving support in order to assure that expectations are realistic.

This article delineates the process for CCT organization and the implementation of a nonmedical support plan for ALS patients/families. In order to work together effectively with compassion and respect, all individuals involved must understand the purpose and role of the nonmedical support system and its ability to accommodate the changes in the life of a patient/family living with ALS.

Organization of the care team services with the goal of reducing family stress while adding support is vital if excellence is to be achieved. Timely implementation of support is critical to the well being of both patient and family. Interacting with the patient in the clinic setting provides the chaplain the opportunity to observe the disease progression and assess needs for altering the care plan. Following is a description of the MSHMC process for creating care teams to serve ALS patients and their families.

**Approaching the family**

The initial approach usually occurs though the chaplain’s contact with patients/families in the ALS clinic. The chaplain’s focus in this setting is to offer the opportunity for developing a congregation care team for a variety of reasons. The “art” of pastoral care at this juncture rests in the chaplain’s ability to discern if such a network may be useful. Consideration is given to the family’s existing resources, the impact of the disease process on the patient/family. Several other considerations also are critical to the process.

Sometimes patients are referred late in the disease process, which changes the type of support that may be offered. In these situations, although a CCT could add support, it may prove to be too overwhelming for the family to incorporate. Further, asking a congregation to come on board at a chaotic time in the disease process may be overwhelming for them as well. Families that were dysfunctional prior to the ALS diagnosis are not likely to follow the CCT guidelines and boundaries. If the chaplain deems it appropriate, she invites the patient/family to review the CCT brochure, which clarifies the details of such support.

If they wish to explore the care team option, follow-up conversations take place at the patient’s home. All family members are encouraged to ask questions and to identify immediate nonmedical support needs as well as those they foresee. Through these discussions, families become familiar with the use of the CCT model—its functions, boundaries and limitations. The family is asked to provide the telephone number of an initial contact person from their congregation, e.g., pastor, parish nurse, person in charge of compassionate care ministry/visitation. Families are given a clear timeline and reassured that they will be “in the driver’s seat” throughout the process.

The most frequently encountered concern is invasion of privacy. The chaplain explains that both job descriptions and expectations of the volunteers are designed to prevent this. One quiet, elderly man, who knew that his wife needed someone to stay with him while she did errands, said, “I’m afraid that people will expect me to talk or they will think that they need to entertain me while they are here. This makes me stressed.” The chaplain reassured him that anyone coming to offer support would understand and respect his wishes at any given time.

Openness is crucial. One patient who was receptive to a care team did not want them to know that he had ALS. The initial exploration of the care team program is a time for trust building as well as an opportunity for the patient to name losses experienced, which sometimes helps to lessen their impact. After one visit, the spouse of the patient said, “I cannot believe the hope you have brought tonight. We trust you, and now we understand and will trust a care team.”

A dedicated homemaker shared, “I am no longer able to cook for my family, and I need assistance.”

**Involving the faith community**

With the family’s wishes to proceed, the chaplain contacts the
faith community. After explaining the family’s need, she offers to meet with interested members of the congregation to educate them about ALS and the CCT concept. During her presentation, the chaplain distributes brochures on ALS and the activities of the ALS clinic and familiarizes her audience with other resources. She identifies critical issues, including the importance of confidentiality, respect for the “home” and awareness of the patient/family members’ limited amount of energy. She stresses the importance of promptness in performing tasks such as delivering meals on time as patients and families often arrange their days so that they will have enough energy to eat together.

This is a time not only to educate potential volunteers about ALS but also to clarify what being a part of an organized nonmedical support team entails. Just hearing “nonmedical” often opens persons to the concept. They are assured that they will not be responsible in medical emergencies beyond calling 911. At the same time, volunteers are alerted to medical interventions, such as suctioning, which they may witness during care team visits.

The chaplain explains how the care team functions and how to become involved. Guidelines for entering the sacredness of a patient’s home are clearly articulated as is the necessity for strict adherence. For example, fatigue is a huge issue for ALS patients. Care team support is not visitation time. Individuals must arrive when scheduled, perform the given task and leave promptly.

Many patients have expressed their gratitude for this instruction:

- I get exhausted when people come and stay and stay.
- Thank you, thank you, for telling everyone to treat me like they treated me before. I am still the same inside.
- You understand the medical part and the spiritual and emotional part and it helps to have you educate our congregation. Now I don’t have to say things over and over. Everyone hears it at once. Now maybe I can go back to church and not get too tired.

The chaplain’s interactive format quickly elicits participants’ concerns. One person commented, “I was afraid to call and offer any help, because I did not understand what was happening to B.” Another shared her own experience with multiple sclerosis, “I have come up with the term, ‘compassionate condescension.’ When I go to a restaurant, the waitress asks my husband what I want to order! Let’s not do this to E.” The chaplain took advantage of this comment to reiterate that persons with ALS retain all senses—touch, taste, smell, sight and hearing—and that it is important to engage these wonderful senses—the parts not being lost.

Though attendance at these presentations has ranged from fifteen to one hundred, the average is sixty-five. Typically the reaction is one of deep gratitude and increased awareness of the needs of fellow congregants. The family is invited, but not required to attend. Often their feeling is that their absence allows the congregation to ask tougher questions about the illness or about their own hesitations and fears, such as that voiced by one attendee: “How can you help us deal with our grief as we witness what is happening to A?”

At the conclusion, sign-up sheets are circulated, each listing one task to meet an identified need of the family. Individuals are asked to indicate their willingness to serve as team leader and to organize volunteers offering a specific support, such as meals.

Organizing the care team

A care team coordinator, who usually is selected prior to the chaplain’s presentation, heads the CCT. Often the family identifies someone they know to fill this role. The coordinator meets with the patient/family to identify their immediate needs. (See the organization chart on p. 25.)

The coordinator’s main responsibility is to support both the patient/family and the volunteers. This is accomplished by seeing that needs are met in a timely fashion, that respect among all participants is reciprocal, that boundaries are maintained and that questions/concerns are promptly addressed.

The coordinator oversees the activities of the team leaders, each of whom is responsible for a group of volunteers assigned to meet a particular patient/family need as mentioned above, e.g., meals, transportation, shopping, respite care, light housekeeping, making small home handicap modifications, such as a small wheelchair ramp. For example, if the family requests two meals five days each week, the care team leader would organize volunteers to prepare and deliver them. Additional team leaders and volunteers are recruited as necessary to meet the additional or changing needs of the family.

The coordinator is the sole contact person for the patient/family.
This protects them from unnecessary calls or complications with communication. All questions and concerns, whether they come from patient, family members or volunteers are funneled through the coordinator.

The chaplain regularly confers with the coordinator and occasionally meets with the team leaders as well. One family chose to coordinate these care team meetings with clinic visits in order to update everyone on the latest developments at the same time.

In one instance, the patient agreed to a number of new inventive supports during a clinic visit, e.g., wheelchair, med-alert necklace and a ramp for her home. By the time she returned home, she was overcome with grief. The following day, her spouse attended the regularly scheduled care team meeting and shared the details as well as his wife’s need for understanding and time to adjust. As a result, both the coordinator and the patient’s pastor stopped by to offer spiritual support later that day. Through further conversation with the spouse, the chaplain was able to clarify several misunderstandings that had occurred and to follow up with the ALS clinic coordinator as well.

As the disease progresses, the chaplain watches for compassion fatigue within the care team. Sometimes the family becomes exhausted and overwhelmed by all of the patient’s needs. One family’s desperation and grief in this situation manifested itself in hostile and disrespectful behavior not only to ALS clinic and palliative care staff but also to the CCT volunteers. In this situation, the chaplain’s guidance, which helped them to maintain support that was both caring and firm in the face of a crumbling family unit, elicited the following from one of the volunteers, “You were there to help us to remember our ongoing role and goal. We needed your reassurance that we were doing nothing wrong, nor were we responsible for the ravages caused by ALS.”

One patient, who was debating whether or not to accept mechanical ventilation, asked a volunteer if care team members would be taught how to care for his ventilator-related needs. The volunteer appropriately referred this question to CCT coordinator who in turn spoke with the chaplain. She “coached” the coordinator for a subsequent conversation with the patient about CCT guidelines and meaning of nonmedical support. At the same time, the patient was assured that such medical support would be available from medical professionals.

Typically, the CCT contract or covenant is for six months. Most teams hold a formal meeting three to four months into the process, which brings together the family members, coordinator, and volunteers to reflect and evaluate the program. Though patients may attend, more often than not they do not. The most frequently encountered issues at this stage are the progression of the disease and the resulting changing needs of the family. Often these are related to the patient/family’s need to further conserve energy or to adapt to the patient’s increasing limitation.

**Response to this initiative**

The Hershey care team model has been used with twelve patients and their families. Most were created for families within a faith community. In one instance, the model was
A care team in action – the story of J and his family

J and M, both 36-years-old, are the parents of three children, ages ten, eight and two. Six months after he was diagnosed with amyotrophic lateral sclerosis (ALS), J had to leave his job as a university professor due to the rapid progression of the disease. M, a registered nurse, also resigned her part-time job in order to care for J and all of the family’s other needs.

J soon experiences difficulty eating and communicating. His mobility has dwindled to the extent that he needs a power chair, and he feels guilty about the care he requires.

M is on overload as the children are acting out as well. The 10-year-old wants to be on a soccer team. The 8-year-old doesn’t understand why Mommy isn’t always available to take her to piano and dancing lessons. The toddler, who senses that something is wrong, has become fretful and clingy. The family is in chaos.

In conversation with the chaplain at the ALS clinic, M says that individuals from the church they attend have offered help, “but when they call, I’m too busy to talk with them, and I don’t know what we need at that point. I do know that there are times that I need help and that I need to have people around me beyond those who are providing medical care to J.”

When the chaplain describes the CCT program and how it may support them, they ask her to contact their pastor. The pastor is most willing to have a knowledgeable person assist the congregation in forming a care team. Persons in the congregation have expressed a desire to help J and M, but they do not know where to begin.

Several weeks later, fifty persons stay on after Sunday services, to participate in the ALS education/care team exploration. During this time they not only learn about ALS as a disease, they are briefed on how to be most helpful to families who have to live with this terminal illness. They begin to understand that breathing machines, communication devices and other medical equipment are now part of J’s daily life. At the same time, it is emphasized that their roles will be as nonmedical caregivers.

Under the direction of the care team coordinator meals are prepared and delivered, lawn care is handled, transportation for the children’s activities is arranged as well as respite time for M, including child care for her toddler. On Monday nights, several friends join J to watch football.

The chaplain continues as liaison, meeting every three months with the team members to assess present needs and/or issues. It is a time for affirmation and support not only for this family caught in the throes of terminal illness, but also for the care team members themselves.

stretched to include people from the spouse’s workplace as members of the volunteer team. In another, the care team coordinator was not a member of the congregation.

Ten of the eleven teams ran smoothly. The eleventh faced added challenges when the couple separated due to ongoing marital issues compounded by the ravages of the disease on one partner. This family dysfunction made it inadvisable to continue, and with the support of the chaplain, the family and the care team decided to end their covenant.

Through this program patients retain a measure of control over the nonmedical aspects of their lives. Their privacy is respected. Typically, they also discover that as they receive help, they also give by providing an opportunity for others to live out their faith through compassionate service. Volunteers often see patients as role models for persevering even when the going gets tough.

Caregivers and spouses acknowledge a sense of continuity with their faith communities. Perhaps most importantly, both caregiver and patient are given a sense of hope:

• I know that this [care team] will be a very helpful thing for us, and it will give some direction for those who want to support us. I’m not always sure how people can help or what to ask people to do.

• This is all so touching to us. We are so overwhelmed, but you have brought us some hope today.

Volunteers appreciate the opportunity to give. With clear job
descriptions and boundaries, they find comfort and reassurance in knowing that what they do is appropriate and helpful and that will be well received. Congregations see the program as an act of faith that answers their call to care. It also develops and reaffirms the breadth and depth of their fellowship. In the words of one team member, “The care team has brought the congregation closer together as we supported L.”

The role of the chaplain is critical to the overall functioning of the program. Initially, she serves as the intermediary between the patient/family and the congregation, helping to shape their working agreement and to insure that the needs of both parties are met. Comments from patients/families include the following:

- I so appreciated the chaplain's sensitivity to our feelings.

- It was a great emotional journey that I have never walked before. The chaplain gave us a sense of direction as to what to expect and the affirmation we so desperately needed.

To provide closure for CCT members following the patient's death, the chaplain offers a time of debriefing. She also sends a letter of appreciation to the pastor of the supporting congregation and offers bereavement follow-up for the family.

No charge is levied for the chaplain's services as her position is funded by the ALS Association, Greater Philadelphia Chapter. Participating congregations are invited to contribute to the ALS Association as it makes this service possible.

**Conclusion**

Through the implementation of the CCT program, ALS patients receive nonmedical support without having to surrender control and management of their lives. This service also helps to mitigate the stress experienced by family members, who receive support at a critical time.

Results of the Penn State MSH Medical Center ALS Clinic quality of life research by Simmons et al. indicate that quality of life is not correlated with measures of physical function and strength, but rather with psychological, existential and social support factors.²

In another study of eighty ALS patients, the single most important factor related to their 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.³

Volunteers know that they are helping in important ways, which will be appreciated. They feel supported in their efforts and know where to turn when they have questions. The congregation's vision of itself as a caring community is reinforced and members are challenged to envision new ways they may make an impact on others' lives.

The success of the CCT model with ALS patients/families challenges chaplains to expand their institutional ministry by stretching it to incorporate faith communities into their healing work in new ways. It also encourages them to explore the viability of this model for use with those who suffer from chronic illnesses, whether or not there is a terminal diagnosis.

**References**