As the patient population shifts from people with acute illness to those with chronic disease, the strictly medical model is proving inadequate. In the words of John L. McKnight: “For all its utility, the medical model always bears a hidden negative assumption that what is important about a person is his or her injury, disease, deficiency, problem, need, empty half. The able, gifted, skilled, capable, and full part of a person is not the focus of the medical model.”

While the focus remains on symptom control, greater emphasis is being given to existential factors contributing to a person’s overall health status. There is a subtle shift from assessing only physical functioning toward measuring a person’s quality of life as well.

Amyotrophic lateral sclerosis (ALS)

Amyotrophic lateral sclerosis (ALS), better known as Lou Gherig’s disease, is a fast-moving, incurable, paralyzing disease. Most patients die within three years; only 10 percent live a decade or more. Typically, it strikes persons either in early adulthood or well-advanced in years. ALS involves the deterioration of the nerve cells, which control voluntary muscle movement. The person’s senses, mind, and involuntary muscles, e.g., heartbeat, gastrointestinal, genito-urinary, bowel, remain functional.

The progression of the disease depends upon which of the two neuron centers are affected. The lower motor center, sometimes referred to as the bulbar motor neurons, because they look like a bulb within the brainstem, controls the large muscles in the extremities as well as the face, mouth and throat. Less is known about the part of the brain which controls the upper motor nerves. Recent research seems to indicate that it controls the direction, smoothness and intensity of the muscle movement. Impairment generally results in spastic movement.

The improvements of medical and nonmedical treatments for people with ALS over the past several years provides a model for the future. This article looks at the clinical progression of the disease and concomitant spiritual issues faced by ALS patients and their families. Research findings and their implications for redefining the role of chaplain through creative interventions are detailed. This includes working outside healthcare institutions to incorporate religious communities into a network of care.

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Though the disease itself cannot be contained, modern medical technology provides the tools for greater compensation throughout its course.

“Most efforts are centered around symptom management. Areas of importance include respiration, nutrition, secretions, communication, pseudo bulbar affect, therapy and exercise, spasticity and cramps, pain, depression and suicide, spirituality and religion, cognitive changes, the development of advance directives, and care at the end of life.”

Typical ALS progression

Although the speed of the progression of ALS varies widely, its typical course does not. It may start in any of the muscle groups, e.g., extremities, speech, swallowing. Eventually, all muscle groups are compromised. As the disease progresses, the patient experiences transitions: walking to wheelchair mobility, talking to alternate forms of communication, eating to tube feeding, breathing to assisted ventilation.

Mobility

As leg muscles deteriorate, the person first requires a cane, progressing to a walker and then to a specially designed wheelchair. When the arm muscles deteriorate, use of the hands declines accordingly.

Patients go through a period of devastation as they try to absorb the diagnosis and its implications. This diagnostic period is followed by identifying and grieving each loss as it occurs. In this grieving process key values of their lives are often invoked. The pastoral goal at this juncture is to acknowledge these transitions and to help patients and families identify specific griefs and focus on pursuing that which continues to give value and enjoyment to life.

Speech

As the person loses control over tongue and jaw muscles, speech deteriorates. Speech therapists may help to slow the deterioration and to suggest alternative ways of communicating.

The willingness of the chaplain to be patient and to make the transitions in communication modes along with the patient, undercuts both loneliness and the fear of being abandoned. The act of “giving voice to” takes on a whole new dimension.

Swallowing

As the person loses the ability to chew and swallow, concerns about choking and aspiration arise. Special training in swallowing and alternative food consistencies may help. Eventually, artificial forms of nutrition delivered through a nasogastric tube or the surgically placed gastric or PEG tube must be considered.

Identification of values and goals is critical at this stage if the chaplain is to help the patient and family wrestle with decisions which they may find anguish and which may have ethical implications.

Breathing

The diaphragm is a muscle, and when it deteriorates, the person experiences difficulty breathing. Initially, noninvasive ventilation, such as bi-level positive airway pressure (BiPAP), may be prescribed. This is the same equipment used by people with sleep apnea. As deterioration continues, a decision regarding assisted ventilation must be made.

At each of these stages, the ALS patient needs to decide whether to accept treatment. As with artificial nutrition, acceptance of assisted ventilation comes with ethical considerations. Even if support is chosen initially, the patient may later request withdrawal. Such a request is likely to involve the healthcare facility’s ethics committee as well as a psychological evaluation.

Some ALS patients desire no nutritional or ventilation intervention, choosing to allow the disease progression to take its natural course. Others choose these supports for a period of time, opting for withdrawal when quality of life becomes an issue. One young mother who choose to decline ventilation told the chaplain, “I am at peace. It is time now for me to go home to God!”

The financial strain and overwhelming impact on family members also may become poignant factors as patients wish to offer peace to their loved ones and to find release for themselves. A nurse educator said, “I have lived well. It is now my time to die well. My family and I are ready.” Helping patients to think through these momentous decisions in the context of their individual circumstances and value systems is critical and is a major contribution of the chaplain.

Coping with ALS

As is evident from the clinical pathway described above, the person with ALS is constantly in the process of grieving the loss of something familiar as well as having to learn something new. Society’s emphasis on individualism, self-reliance, and personal autonomy makes it difficult for most people to imagine that a life with extreme disability and dependence on others is worth living. Despite this, many ALS patients do continue to enjoy life. This apparent contradiction has lead to several research
studies aimed at identifying those characteristics, which help individuals to cope.

A 1998 study by Jenny M. Young and Paula McNicoll found that prior to diagnosis, eleven factors were most often cited as needed for life satisfaction. People with ALS who coped well with the disease cited six as being particularly helpful: use of cognitive reappraisal, reframing, and intellectual stimulation, development of wisdom and vital importance of interpersonal relationships. Relationships to spouse, relationship to children and sense of humor ranked highest at both measuring points.

The variable, which showed the greatest increase from pre to postdiagnosis, was other relationships. The most powerful themes to emerge were the use of cognitive reappraisal, reframing, and intellectual stimulation as coping mechanisms; the development of wisdom; and the vital importance of interpersonal relationships. 

Young-Ru Tang notes that “living with the caregiver, spirituality, and social support statistically were significant predictors of a terminally ill patient’s quality of life in original, empirical and conceptual approaches.”

Research by R. A. Robbins and colleagues verifies these findings: “Despite a progressive decline in physical function as measured by the ALS-specific function score, the general QOL [quality of life] and religiosity scores changed little. In contrast, the ALS-specific health-related QOL score is primarily a measure of physical function. QOL instruments that assess spiritual, religious, and psychological factors produce different results than those obtained using measures of physical function alone.” (italics added)

Taking an inverse approach by studying helplessness, J. M. Plahuta and colleagues found that “health locus of control and purpose in life were significant predictors of hopelessness among ALS patients. Other factors, including socioeconmic and demographic variables, variables measuring length and severity of illness, and additional psychosocial variables (social support satisfaction and degree to which spiritual beliefs help to cope with ALS) were not significant predictors of hopelessness.”

Research at the ALS clinic referenced later in this article found that “QOL was not significantly correlated with religiosity at entry. Over time, a significant relationship developed between QOL and total, public, and private religiousness.”

Barbara A. Bremer and G. LoCoco concur: “Over time, self-perception of health and religiosity were shown to be significantly correlated with QOL.”

Interestingly, patients and caregivers who endorsed spirituality as a significant domain reported better QOL.”

Thus, in general, research on quality of life and factors contributing to it in ALS patients has led to the following consensus: “Greater understanding of the nature of life satisfaction despite severe physical limitations and of the ALS patients’ definition of purpose, meaning and quality in their lives is important for the health care practitioners so that they can incorporate these factors.”

ALS Clinic at Hershey Medical Center

The Hershey Medical Center’s ALS Clinic is affiliated with the Greater Philadelphia Chapter of the ALS Association. The Muscular Dystrophy Association also provides support. Since its inception in 1995, the number of ALS clinic team members has risen from two to fourteen. Approximately one hundred twenty patients and families are followed at any given time.

Patients usually visit the clinic for a half-day every three months. Depending upon their medical needs, they may have appointments with one or more of the following specialists: neurologist, pulmonologist, clinical nurse specialist, staff nurse, physical therapist, occupational therapist, speech pathologist, chaplain, social worker, mental health counselor, and nutritionist.

The research referred to earlier in this article, supported the addition of a chaplain to the ALS Clinic. Initially, a clinical pastoral education resident filled this role, which resulted in a lack of continuity as there was frequent turnover. In 2002, the status was changed to a staff position. Nevertheless, because of the fast-paced nature of the work and resulting infrequent contacts with many clinical staff, as well as preconceived notions regarding clergy in general and/or a lack of experience in working with chaplains, it took nearly two years before the chaplain was fully-incorporated into the interdisciplinary team.

The chaplain nurtured staff relationships through snippets of hallway conversations as she waited with clinicians for her turn to visit a particular patient. These initially tentative conversations as well as observations of the positive changes in
patients and families following the chaplain’s visit have led to staff giving her heads-up comments such as “be aware of…..”

Despite this spirit of cooperation, the importance of spiritual care may get lost in patients’ crowded medical agendas. For example, when a patient is being transferred from clinic care to hospice care, getting equipment becomes a priority, and the emotional and spiritual impact of such a transition may be overlooked.

It is the chaplain’s unique contribution to remain focused exclusively on the patient and family. With no other agenda, the chaplain’s presence becomes a stabilizing influence, a fact that was quickly recognized when one family became very upset at her absence.

**Themes of spiritual caregiving**

One of the objectives of Hersey’s ALS spiritual care program is to develop pastoral interventions which encourage and support the enjoyment of life despite the physical deterioration. In the five years that the coauthor of this article has worked with ALS patients, an overarching theme has presented itself—that of a common thread that weaves through the many issues faced by these individuals. Helping individuals to identify and to enjoy that which gives their lives meaning is central. “I have come to see my work as helping the patient and family transform their web of life into a labyrinth.” That transformation takes place over many of the strands in the web.

Living life with the cruel disease of ALS may quickly leave the patient feeling trapped in a body with no way out. Together with the chaplain, patients explore ways to find meaning and hope, ways to embrace choices open to them, and ways to move forward in faith and trust. This transforms their tangled web of chaos and despair into an open labyrinth of order, freedom, and hope.

**Emotional validation**

The chaplain’s first task involves helping patients to realize that as their bodies change, so do their emotions and spirits, and to recognize the truth of any given situation. She also helps them to see that their questions, thoughts, feelings, and emotions are not right or wrong; they just are. Each is worthy of being acknowledged; each must be accepted and dealt with as the individual is able. Each belongs to the patient alone, just as grief does. To minimize any of them is to rob the patient of what is needed in the present moment—as painful as that may be. Ultimately, it is the path to “health in the face of adversity.” One patient to whom these words were said responded through her tears, “Those words you have spoken are like gold to me.”

**Spiritual vacillation**

Hearing and honoring vacillations in spiritual thought and practice during the experience of ALS is important as well. Such changes are not signs of spiritual weakness, but rather of an active, searching, and dedicated mind and soul. The clinic makes available a book of thoughts, poetry, and prayers written by a person with ALS. For some, the harsh reality of the patient’s spiritual struggle is too difficult to read; however, one patient commented, “This book is now my inspiration.”

**Perception of God/the Divine**

Each person’s image of God reflects a sense of self and of the world. Sometimes, the image is one of comfort; at other times, one of pain. A different glimpse of God may help patients to see themselves differently. After several clinic visits, a patient said that the chaplain had helped her think of God not as “problem solver,” but as “constant presence” in all those areas of her life that could not be “solved.”

**Life purpose and personal worth**

Purpose and worth are themes that help to restore the crumbling self-image that is a result of the ravages of ALS. The goal is to help patients explore ways in which their lives still have worth. Before losing his ability to speak, a young father of four spent hours composing CDs for each of his children. He found that in the process he did a life review, which not only changed his life, it gifted his family immeasurably.

**Human limitations in understanding**

Acceptance of human limitations in thought and understanding may bring both frustration and comfort. Coming to terms with the fact that so much of life is a mystery often provides a breakthrough for patients. “I’m learning to be more at peace with my unanswered questions,” a patient said with firm resolve. “We all need to recognize our limitations without understanding them…. It’s a struggle.”

**Present and future hope**

Hope is a theme, which teases the ALS patient. Giving guidance on how to claim both appropriate hope in the now and eternal hope after death encourages thought, anticipation, and a realization of life that can remain rich and meaningful even in the face of suffering and adversity. A young mother of three struggled with feelings of failure and hopelessness until she
Pastoral interventions

As the movement for spiritual assessment and pastoral interventions has developed, many models are becoming available. For example, Nurse’s Handbook for Spiritual Care: Standing on Holy Ground by Mary Elizabeth O’Brien provides helpful categories for spiritual assessments. In working with ALS patients and their families the following types of pastoral interventions have been most fruitful.

Establishing rapport with ALS patients

As a patient’s first visit to the clinic often is overwhelming, the chaplain’s initial visit is limited to establishing a warm and trusting relationship. She simply lets patients know that she is there to listen to their struggles and to what gives meaning to their lives during this chaotic time.

Clinic appointments are three months apart, and the chaplain initially followed up with telephone calls. However, many patients had difficulty talking and thus conversing by phone was awkward.

Writing has proved to be a more practical means of communication. The chaplain uses note cards with photos of tranquil settings, rephrasing what she had heard during the introductory conversation within a framework of concern for what the patient is going through. She concludes each note with the hope that she will be able to touch base with the patient during the next clinic appointment.

This approach has generated many warm responses on subsequent clinic visits. Patients speak about how much the cards meant to them, and frequently this led into a discussion of current concerns or desires. For example, one patient with bulbar ALS wanted to have a prayer partner, and her church had offered to provide one. The chaplain provided coaching to address the difficulty in understanding the patient’s speech. The success of this prayer partnership was the first thing the patient mentioned at her next clinic visit.

Providing additional modes of support

Several support groups are provided for patients and/or families, including a resource group, led by the mental health counselor. Various printed materials are offered as well. One book that parents deeply value is How to Help Children through a Parent’s Serious Illness by Kathleen McCue. Another, written for adults, is Learning to Fall: the Blessings of an Imperfect Life, authored by Philip Simmons, who was diagnosed with ALS in the prime of his life. For a complete resource list, contact Barbara Brunk Gascho (bgascho@paonline.com).

Creating new rituals

Rituals often have been used to help people through transitions in their life or status. Their use can be profoundly healing for the ill person. The formalized symbolic action of a ritual can guide one to find meaning in time of significant life events. Rituals connect our joys, our longings, our burdens with the Divine. They offer an opening for one to experience release and hope.

Recently there has been a resurgence of interest in the importance and function of rituals in pastoral care. Of particular interest is creating rituals for people in specialized circumstances. The “blessing of the wheelchair,” marks a significant transition in the life of people with ALS. Participation of the ALS patient, family members, and staff gives symbolic voice to their collective efforts. The ritual of “holding the cross,” offered to Christian patients, utilizes a piece of wood carved into the shape of a cross, which has been
slightly offset to fit comfortably in a person’s hand.

Impromptu rituals, which connect people to what they treasure becomes very important. An example of this occurred when the chaplain put the hand of a young mother, who was on a ventilator, into a bag of flour and witnessed her joyful response. The chaplain knew the woman enjoyed baking and later discovered that she had once operated a bakeshop.

Families often are comforted by continuing connections to the chaplain who has accompanied them throughout the difficult journey of ALS. She regularly meets with surviving spouses for one-on-one bereavement follow-ups. In those moments when grief seems unbearable, a candle is lit to bring light into the darkness, to bring hope out of grief and loss. She also sends personal invitations to each surviving family for the monthly Service of Remembrance, held at the Medical Center Chapel.

Arranging home visitation

In 2004, additional grant monies enabled the ALS program to include home visitation. Topics addressed in familiar surroundings, where patients feel safe and have privacy, are vastly different from those raised in the clinic. The conversations are more open; both patients and families are appreciative of this personal care.

One patient, on the brink of death for days, was able to acknowledge the presence of the chaplain, who offered him a benediction: “The Lord bless you and keep you and give you peace.” He died an hour later. Later, his wife called and said through her tears, “You came with your benediction, and you walked him home to God.”

Connecting to faith communities

Inevitably, conversations turn to the needs of the patient and family. Though faith communities often are eager to help, they may be unaware of special needs relative to ALS. The chaplain works with the coordinator of the congregational care team to arrange appropriate education for those interested in serving a particular family.

During the orientation, the chaplain initiates a frank discussion of things to be alert to, such as the patient or family’s energy level, difficulty in communicating, and the types of things they are likely to need, e.g., short visits, meals, respite care, light housekeeping, transportation, help in sorting through the medical and insurance papers. She also provides the opportunity for caregivers to voice equally frank questions and concerns. Following this general meeting, the chaplain meets with the person chosen with family approval to lead the care team in order to establish a covenant between the patient, family, and care team participants.

Several care teams have been established, and the feedback has been consistently positive. Patients see this as a way to lift some of the burden from their families. They appreciate people who are willing just to visit and to “be with.” Expectations of conversation are eliminated because the fatigue factor is understood. Concerns about what to do during the visit (watch TV, read a book to, sit in silence) have been worked out ahead of time.

Families say that they feel less isolated and lonely. Care team support guards against their becoming over fatigued or burned out. As a result of their ongoing connection to the faith community, when death does come, relationships are in place to see them through the grieving process.

Care team members express astonishment at the courage and creativity of patients and families. Knowing that their help is important and means a lot to those on the receiving end also is a key factor in their dedication. They also are appreciative of the chaplain’s role. One person put it this way: “I would have been afraid to do this without someone as a back-up, and as the chaplain was not a church member, she could raise issues that others might not have been comfortable with.” Further, the chaplain helps to draw clear boundaries between medical and spiritual support. When one patient asked care team members for help as he was placed on a ventilator, the chaplain intervened to ascertain that qualified medical personnel took on that responsibility.

The intentional focus on meeting the unique needs of each patient has led to new iterations of the care team. In the newest, the care coordinator is a person from the community but not a member of the supporting congregation. Thus, the web of support continually expands.

Impact on the chaplain

In the process of providing care to ALS patients, the chaplain has been transformed. Often patients are not connected to a congregation. When the topic comes up, they cast their eyes down and apologize. However, when they are asked what gives meaning and significance to their lives, the images are endless.

The chaplain continually is surprised and touched by the unique spiritual journeys she encounters and in which she is invited to take part. One patient talked about being able
to sit on the porch and watch the sunrise. Another loved his John Deere tractor. His perch on the high seat had become his sanctuary. Fiercely independent, he would exert every ounce of energy his debilitated body possessed to reach this summit, his place to view the fields once more, to reconnect with former days, and to open his world to God.

The chaplain is awestruck by the capability of ALS patients to reach at once into the depths of their humanity and outward to the fringes of their lives and to find great strength and courage in both. Their shared stories have become models for her own journey and encouraged her to explore the depth of her own soul. It has clarified her role as chaplain, captured in these words of Nancy Guthrie:

“Our task is not to decipher exactly how all of life’s pieces fit together and what they all mean, but to remain faithful and obedient to God who knows all mysteries.”

On a personal level, the chaplain has become much more aware of what gives her life meaning. Her awareness of life’s impermanence has been greatly heightened, resulting in a greater desire to savor the moment. The recognition of her own limits, which has caused her to look closely at where best to invest her energies, has opened a door to a richer appreciation of life, as captured in these lines from the poem “Mystery”:

A person who moves with difficulty may have a clearer sense of destination.

Conclusion
As the chronically ill population increases, the healthcare system needs to develop new ways to provide continuity of care. The current emphasis is on cure of acute illness. When that is not possible, patients and their families often are left to fend for themselves. Efforts to deal with issues posed by ALS patients and their families provide models for spiritual care systems to interface with medical support in ways which are transferable to other situations of chronicity as well as to the frail elderly.

References
4 Ibid.
5 Woung-Ru Tang, “terminally Ill Patients and Their Caregivers’ Quality of Life” (PhD diss., University of Kansas 2001), 231.
11 Young and McNicoll, “Against all odds,” 38.
15 Nancy Guthrie, Holding on to Hope (Wheaton, IL: Tyndale House Publishing, 2002), 82.