

MAKING "CARING CONNECTIONS"

A New Program Enhances End-of-Life Care in a Retirement Community in Ohio

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"Caring Connections" is an innovative program at Laurel Lake Retirement Community (LLRC), a 450-resident facility in Hudson, OH. LLRC comprises independent living, assisted living, and nursing home care. The facility offers a responsible approach to retirement planning through what it calls a "life care contract." The contract guarantees residents a lifetime of high-quality services, whatever the level of need, and includes a safeguard to limit long-term health care costs.

LLRC's mission is to enhance the quality of life for older adults by encouraging wellness, self-determination, and independence throughout life's transitions. The staff takes care to develop supportive relationships with residents from the moment the latter enter the facility. Caring Connections was created to address the uniqueness and complexity of dying.

Caring Connections is based on the belief that the long-term care environment can be a supportive place for dying persons and their families. LLRC's leaders recognize that they have a unique opportunity to help change the culture of contemporary society as it relates to death and dying. Over the past several years, the facility has provided educational programs on supportive care of the dying for its entire professional and nonprofessional staffs, including administrative, health care, dietary, and housekeeping personnel. This education, which includes small group discussions, has given staff members a keener awareness of bereavement needs. The facility has also formed support groups for residents and staff needing help with grief and loss and a group (called "Children of Aging Parents") to help children cope with a parent's aging and decline. Memorial services, in which both staff and residents participate, are held routinely for residents who have died.

TLC GIVERS

A significant piece of the groundwork for Caring Connections was done in 1997 when five LLRC residents (assisted by Sr. Marie Ruegg, HM, one of this article's authors, at that time the facility's director of mission and planning), recognized the need for a more comprehensive approach to grief, loss, and dying. This group saw that whereas residents' physical and social needs were well-met, their emotional and spiritual needs received less attention.

The five residents wrote a mission statement and explored potential programs that would enable them to serve their peers in a volunteer capacity. These initial steps resulted in establishment of a unique volunteer program that they called Tender Loving Caregivers, or "TLC Givers," in short. The TLC Givers participated in a 12-hour training program that included topics



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on reflective listening; valuing individual differences and all faith traditions; recognizing feelings; and addressing emotional needs related to grief, loss, and dying. TLC Givers help their peers as they make the transition from independent to dependent care, become widows or widowers, or deal with terminal illness and death. Among the TLC Givers—who now include elderly volunteers from outside LLRC—are retired teachers, social workers, nurses, a physician, and a minister; they range in age from 62 to 96.

The TLC Givers program provides an extra layer of supportive care for residents at LLRC, with particular emphasis on the spiritual aspects of aging. TLC Givers are trained to be a comforting, encouraging presence for residents in need. They spend quality time with other residents, listening reflectively to concerns, and showing—with a smile, touch, or kind word—that they care. The lives of both caregivers and care receivers are enriched through this network of support.

TLC Givers have learned that, as volunteers, they also benefit from open, honest discussion of life's losses and transitions. The program has become very popular. In 2002, over 200 LLRC residents and some 60 volunteers from the larger community together gave more than 10,000 hours to the facility's residents. Today, TLC Givers constitute a seamless networking of volunteers in the Caring Connections program.

THE CARING CONNECTIONS PROGRAM

Training for Caring Connections began in March 2000. The program's goal has been to train health care staff and volunteer caregivers to enhance end-of-life care for long-term care residents and their families. The project has been implemented in three phases.

Phase 1 Staff members and volunteers attended a 30-hour education program on hospice principles. These sessions prepared caregivers to respond to the spiritual, emotional, and physical needs of people facing the end of life. The program involved:

- The assessment and evaluation of the physical, emotional, and spiritual dimensions of end-of-life care
- The exploration of attitudes, values, and beliefs associated with end-of-life care
- The investigation of ways that volunteers and staff can work together to meet the needs of residents and their families

Caregivers were taught to integrate interventions into routine care for all residents.

Phase 2 Staff members and volunteers applied the educational principles they learned to actual

death and dying experiences they had witnessed. Following a method created by the Loyola Institute for Ministry, they gathered in "learning groups" to discuss their experiences concerning end-of-life care.¹ These sessions provided a forum in which staff and volunteers learn to process and share grief and bereavement issues and experiences and give support to other participants.

Phase 3 Staff members and volunteers evaluated project activities to assess the success of the integration of emotional, spiritual, and physical care into daily care and determine their feasibility for replication at other long-term care facilities.

DESCRIBING THE PROBLEM

The TLC Givers program and the education forums and discussions held for staff members and volunteers were foundational to the Caring Connections project. Indeed, promotion of compassionate and comprehensive end-of-life care for residents and their families became the *raison d'être* for development of Caring Connections.

The program acknowledges the inevitability and certainty of death and enhances understanding of the uniqueness and complexity of dying in long-term care. It acknowledges, for example, that chronically ill or frail long-term residents are as likely to die suddenly as they are to live several months (let alone years) with the disability that brought them to the facility.

The complexity of illness or disability may disguise the dying process, making it difficult for the staff to plan and provide adequately for end-of-life care. Standard assessments and routine care interventions do not include end-of-life care and are not focused on treating the whole person. Deficits in end-of-life care were recognized by the

Testimony from LTC Givers

People who have participated in the TLC Givers program have been very positive in their responses to it. The following are some of those responses:

- "To help someone at this time in my life is a gift. TLC Givers gives me the encouragement and faith to make a difference. The fears I have in reaching out are infinitely less than the gifts experienced with each new friend."
- "My sensitivity to those who suffer has been heightened by the TLC Givers program. I find I now recognize the lonely person sitting by [himself or herself] watching the world go by. . . . Therefore, I sit down beside [him or her] and visit."
- "I had the privilege of being with both of my parents as they were dying, and I consider it to be a gift to sit with each person dying at Laurel Lake."

Institute of Medicine's 1997 study, which reported that—despite efforts to improve the general quality of nursing home care—end-of-life care was neither well understood nor included in most nursing home care plans.²

The traditional emphasis on "cure" runs counter to the reality that many long-term care residents derive only minimal benefit from intrusive treatments and aggressive interventions. Many would benefit from an approach that responds comprehensively and compassionately to physical, emotional, and spiritual end-of-life needs.

RESPONDING TO THE NEED

The Caring Connections program is based on the belief that, with the appropriate education of staff and volunteers, any long-term care facility can be a supportive care center for dying residents and their loved ones. Caring Connections is resident- and family-centered and responsive to a complex and changing care environment.

As noted, the first Caring Connections training session was held in March 2000. Additional sessions were held that June and in June 2001. Ninety-five participants—including nurses, nursing assistants, housekeeping and dietary staff, administrative personnel, residents, family members, and community volunteers—received training as caregivers.

The education coordinator from the Hospice of the Western Reserve, Cleveland, provided instruction on pain assessment, symptom management, and identifying the emotional needs of people facing death. The hospice's spiritual care coordinator instructed participants in that aspect of end-of-life care. The hospice's chaplain provided information about spiritual assessments and interventions and grief and bereavement care. A geriatrician with expertise in end-of-life care presented a medical perspective on dying in old age and in long-term care. The sessions' facilitators created an environment in which participants felt free to talk openly about death and dying. The sessions taught participants how to integrate physical, emotional, and spiritual care into daily caregiving.

Participants then formed small groups that, meet-

The first Caring Connections training session was held in March 2000.

ing monthly, began to integrate information from the training program with their own experiences as caregivers. These groups rely on the "multiplier effect": Rather than employing the hierarchical "expert" lecture format, peers use their personal knowledge and experience to teach each other. The result is a culture of continuous, synergistic learning in a community of individuals who share roles and

goals. In such a culture, death experiences can be addressed on a case-by-case basis, thereby ensuring that end-of-life care is viewed from the central position of the individual and family. Through this process, caregivers integrate educational concepts and personal meanings that help them become more comfortable in dealing with the end of life.

The benefits derived from Caring Connections can be seen in even routine activities at LLRC. For example, the facility's "resident review team" meets weekly to approve the admission of new residents into independent living and to assess the status of current independent-living residents, to determine whether the latter need adjustments in the level of care they receive. Family members are invited to these meetings. Taking note of a wide range of information, including that provided by family members, the team is better able to form a multidimensional picture of the resident's current status and address his or her needs.

BENEFITS AND OUTCOMES

Caring Connection has inspired all who live and work at LLRC to take an increased interest in continuing education and to renew their commitment to meet the needs of those facing the end of life. Its education program has strengthened communication among staff, volunteers, residents, and residents' families, positively influencing the quality of end-of-life care. Caring Connections has:

- Enhanced interdisciplinary team care in the management of problems related to pain, dyspnea, anxiety, and depression
- Increased knowledge about complementary and alternative methods of pain and symptom relief
- Increased sensitivity to and comfort with various cultural and faith traditions

- Increased use of resources for spiritual support for residents and families, including employment of a full-time chaplain

- Improved the assessment and management of symptoms at the end of life

- Increased use of hospice care

Participants in the Caring Connections program have a better understanding of palliative care, appropriate pain treatment, and the importance of giving families choices in care. They also have an improved ability to distinguish between suffering and physical pain.

Staff training like that obtained in Caring Connections seems to be crucial in promoting compassionate end-of-life care for residents and their families. Assessments of participants' spiritual well-being show that they have developed considerable insight into their personal strengths and are aware of spiritual resources. For example, participants recognized prayer as an important part of their lives, were understanding of others' beliefs, were able to give and receive love, were goal oriented, and believed in and found meaning in a supreme being. These findings confirm the importance of incorporating content regarding spirituality into the work environment; they show how spirituality relates to providing physical and emotional care.

LOOKING TO THE FUTURE

Phase 3 of Caring Connections has involved evaluating the program and sharing what has been learned with other long-term care communities. Of course, we see challenges ahead. One thing needed is increased physician involvement in the training of those who provide end-of-life care. As primary care providers to nursing home residents, physicians play an important role in end-of-life care. In the future, we hope to include physicians in Caring Connections training sessions. A presentation by a physician gives a perspective that enhances understanding of the difficult medical issues in end-of-life care.

LLRC staff frequently say that they have derived numerous benefits from the program, especially the preparation it has given them in providing emotional care and in considering residents' and

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family members' spiritual concerns. However, we should be integrating these verbal reports into ongoing resident care. We are improving documentation in the resident record regarding emotional and spiritual care. LLRC has recently added a chaplain to its staff, which should advance these efforts.

Another challenge in long-term care is staff turnover, particularly among nursing assis-

tants. LLRC has made a priority of, not just providing its staff with frequent training sessions, but also adapting those sessions to the staff's demanding and changing schedules. Monthly "learning group" sessions with staff members, for example, have not been as successful as the similar sessions for TLC Givers. To be successful, group sessions require flexibility and continual adjustments to accommodate the ever-changing demands of daily care routines. We have been more successful in including hospice principles in the training program for nursing assistants.

As we look to the future and the challenges it is sure to bring, we are confident that residents and their families will continue to benefit from the Caring Connections program. We know that LLRC's staff will be better equipped to provide the care needed for residents at the end of life. We are confident that continued efforts to build on this innovative program will be far reaching and especially valuable to those spending their final days in long-term care. □

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NOTES

1. Loyola Institute for Ministry, *Loyola Institute for Ministry: Extension Program Prospectus*, Loyola University of New Orleans, New Orleans, 1997.
2. Committee on Care at the End of Life, *Approaching Death: Improving Care at the End of Life*, National Academy Press, Washington, DC, 1997.