Living and Dying Well: A Whole-person Approach

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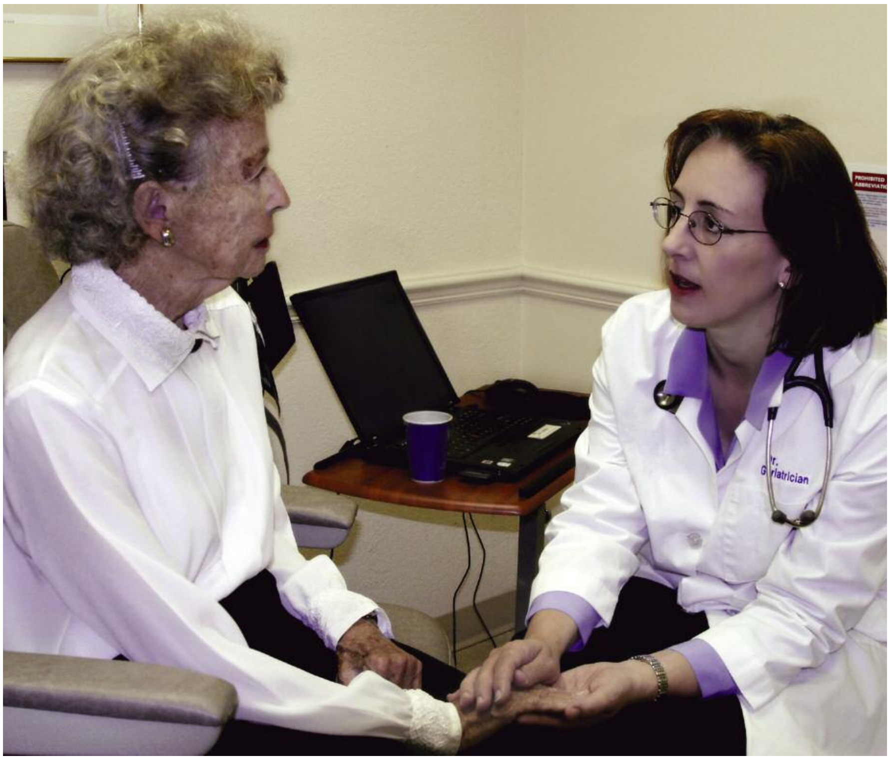
Lakeview Village is committed to staying at the forefront of best practices. As part of this focus, the 43-year-old continuing-care retirement community (CCRC) with 800-plus residents and 300-plus employees on 96 acres in Lenexa, KS, is undergoing a gradual transformation into a whole-person wellness (WPW) community. Whole-person wellness—"everyone, everything, and everywhere"—has inevitably affected our approach to palliative care (see "Creating Whole-person Wellness" in the July/August issue of *ALC* at: www.assistedlivingconsult.com/issues/03-04/alc78-Wellness-719.pdf). This article highlights processes and outcomes that can be used to ensure every resident an opportunity to live well through the last chapter of her or his life.



Assembling a Think Tank

The CCRC has been working for more than 6 months to educate and commit its entire community to whole-person wellness. A short-term think tank was assembled to consider WPW adaptations to the organization's award-winning palliative care program. This think tank consisted of the administrator and director of nursing, the authors, the active living services director, and a hospice nurse.

All members of the think tank were familiar with WPW principles and thinking. Furthermore, all had personal and professional experience with palliative and/or hospice care. All routinely work with the facility-developed definition of WPW:

> WPW is multidimensional, positive health leading to a satisfying quality of life and a sense of well-being—for individuals and for the community as a whole. By *multidimensional* we mean the physical, spiritual, intellectual, vocational, social, and emotional aspects of personhood and community life.

Palliative Care in Keeping with WPW

Our think tank examined its existing definition of palliative care and found certain words or phrases, never noticed before, consistent with paternalism on the organization's part and passivity on the resident's part. The old definition, subtly inconsistent with the principles of WPW, was slightly revised to the following:

> Palliative care is an active, collaborative approach to care that enhances the person's quality of life, when he or she decides not to pursue curative approaches. It includes (1) focus on experiences most comforting and enriching to the whole person; (2) comprehensive support to family and friends; and (3) effective pain and symptom management.

Our previous definition dealt primarily with disease, pain, and symptom management and focused on the person's being "done to." That definition ignored or undervalued the person's experience, active participation in decision making, and ability to collaborate. According to our WPW definition, all 6 dimensions—physical, emotional, intellectual, social, vocational, and spiritual—are intrinsic to every aspect of palliative and end-of-life care and must therefore be specifically considered.

We found definition setting an extremely valuable place to begin. Thesaurus and dictionary at hand, we were forced to rethink the conceptual underpinnings of palliative care in a WPW framework. Discussion of the concepts consistently prompted sharing of real-life examples illustrating end-of-life care delivery—from excellent to appalling—at our own facility and elsewhere. The definition setting thus provided a rich foundation for all of our subsequent discussions.

Dying Well versus Dying Poorly

Coming to any clarity on the charged topic of dying well required a spirited discussion, even among a group of people who deal with dying all the time. Most important, we agreed that death is not the opposite of life: it is part of life. Dying well is a critical aspect of living well. As any professional caregiver knows, there is a vocational aspect to dying well: how one dies inevitably provides lessons to family members and caregivers. These lessons become a heritage for the affected family members and caregivers—lessons that they subsequently pass along, most often without words, to family members and friends. The affected bystander absorbs the lessons to inform his or her own dying process. A valuable question for each of us—staff, resident, family member, or friend—is: If this were your own death, how would you want it?

From these considerations, the think tank distilled the major contrasts between dying well and dying poorly (Table 1).

Table 1.
Differences between Dying Well or Poorly

Dying Well	Dying Poorly
Being prepared, in the moment, and feeling at peace; having a sense of closure and feeling "permission" to die	Feeling fearful, hopeless, and/or victimized; fighting death
Resolving losses and/or grieving to release them	Being burdened by regrets
Showing grace, dignity, and a sense of purpose—giving oneself away to the people around one	Feeling burdensome, withdrawn, or antagonistic
Having all dimensions of wellness—physical, emotional, spiritual, social, intellectual, and vocational—addressed; being treated in a personal and individualized way	Being treated in a clinical way, with focus on medical concerns
Having understanding and acceptance by family, friends, and caregivers	Feeling lonely, without environmental support; children in strife
Participating in management of pain and symptoms; having sufficient "clinical peace" to focus on nonphysical elements	Having uncontrolled symptoms and/or unacceptable pain, with a primary focus on physical difficulties

Transtheoretical Stages of Behavior Change

Implicit in a community commitment to WPW is the faith that people have an innate desire to live a positive, optimistic, and health-balanced life. Despite the innate desire, many people aren't sure where to start. The WPW basis for a gradual shift to wellness is Prochaska's Transtheoretical Stages of Behavior Change.[1] These stages occur along a continuum, from total unawareness of the desired behavior (precontemplation) to awareness and interest (contemplation), to exercising the behavior (preparation), embarking on the behavior (action), and making it a habit (maintenance). A final stage (relapse) can occur when the behavior is not reinforced by one's community. However, relapses never return to precontemplation.

An underlying assumption in WPW is that we must always meet people where they are. Prochaska's behavior-change model factors implicitly into excellence in end-of-life care, because staff members can learn and use these stages to recognize "where someone is" in his or her own life process. Staff who do not understand these stages often underestimate the importance of the contemplation and preparation stages. Without appreciating these stages, staff may give positive feedback only to people in the action and maintenance stages, and no encouragement or respect for people in a "just thinking about it" stage. In fact, of all the stages, contemplation and preparation often require the most mental and emotional work, and therefore require the most time and support. Staff need assistance in understanding their own change processes and stages as well, to clearly recognize progress in others.

Talking about Palliative Care

Attention to the contemplation stage is extremely important in helping a resident and his or her family members explore the option of palliative care. It is most often a step-wise decision to move away from seeking further diagnostic information and curative treatment because ideally the quality of life remaining takes on more significance. Accordingly, no one knowledgeable about WPW expects a quick decision when the issue of palliative care arises. Staff members educated and equipped for WPW know to begin giving information in small, simple bites. They extend patience and accessibility when a person begins to digest this information and subtly ask for more. Just as important, some residents and family members benefit from understanding the stages of behavior change so they can recognize and respect their own processes and those of their loved one.

Staff members also have to stay mindful and accepting of those residents who choose, for whatever reason, to stay in the precontemplation phase. Such persons, not wanting to create advance directives or take any other planning steps, still benefit from the environment a WPW community provides: their individuality and choices are honored, and people around them continue to support positive options. The environment provides continuous subtle encouragement toward choosing positive end-of-life experiences.

Assisted Living and Transitional/Palliative Care

An assisted living (AL) setting offers distinct benefits in implementing WPW transitional and palliative care. Such benefits include the comprehensive activities planning and relatively high level of family involvement; these promote a sensitive exploration of the person's expectations and consequent service contract.

AL facilities can utilize outcomes-based planning as an effective strategy with the overall goal that each person—resident, family member, and staff member—collaborates for a quality end-of-life experience. Through this approach, a community can facilitate the journey of grieving and dying in a way that supports all dimensions of personhood.

Essential components within an AL environment include:

- Collecting extensive lifestyle and historical information when a person enters the community to emphasize strengths and respect values and preferences. Whatever has been extremely important to a person throughout her or his life remains so to the end,[2] and serves as an important guidepost for WPW decision making. We have found that the initial, personal "life information" so naturally collected by marketing staff and admissions coordinators often gets lost in the rush of the resident's admission and acclimation processes. This information, when captured, illuminates some of the idiosyncratic elements that make life meaningful for each person. It provides valuable reference points if and when the person loses cognitive or communication skills.

> **Palliative care is an active, collaborative approach to care that enhances the person's quality of life.**

- Ensuring that the organizational elements consistent with WPW are in place to support the initiative.[3]
- Recognizing and genuinely accepting each person's starting point along the Transtheoretical Model and meeting each person where he or she is in the process.
- Offering suitable programs and materials, language, and actions—often different for different stages—to help people move through the process. This approach includes educating people about palliative care, hospice care, Do Not Resuscitate orders, and resuscitation outcomes—what each of these is, what they mean and imply, and what proactive comfort care options they suggest.
- Focusing on residents first, rather than family members, because residents often show much more willingness than adult children to address end-of-life issues. Of course, well-designed WPW palliative care gives both residents and their family the gifts of words, concepts, social supports, information, and other tools to further their thinking and communication with one another.

Modifications for Cognitive Sensory Loss

It is a distinct challenge to provide quality end-of-life care congruent with WPW to individuals with cognitive or sensory loss. This challenge requires an additional widely recognized skill set: the empathic skills and commitment to communicate with and respect people with such losses.[4,5] To meet and maximize the person's areas of strength, such losses may necessitate creative changes in clinical and personal care procedures.

Being known—personally and intimately—is a powerful component in any person's quality of life; it is particularly critical in successful palliative care. Tools such as the person's life plan provide the detailed life information that helps staff focus on strengths and preferences when a resident is very ill, confused, or nonverbal. An extensive social history becomes more important than ever in identifying strengths and preferences.

Adapting Management Procedures

The transformation we are describing requires significant background work on the part of the organization,[3] with these being the most important components.

Examine Your Organization

Examine your current vocabulary, ceremonies, and practices around palliative and end-of-life care. Do you have a bedside service after a person dies? How is the grief of direct caregivers respected? Do you facilitate caregivers' and other residents' attending funerals and memorial services? Does the caregiving team, within 48 hours of a death, do a self-evaluation of the quality of the person's dying process?

Lakeview Village has used a creative-thinking technique with groups of employees: "If we are a WPW organization, what will...[insert the procedure, process, or situation] look, feel, sound like? Does ours? If not, what do we need to do, to get to the outcome we want?"

Identify and build on your preexisting strengths. For instance, if knowing a person's history, preferences, and life plan is a fundamental starting point, then a valuable first step is to identify the staff members who regularly elicit such information—especially from people with reduced verbal or cognitive skills—and provide a way for this skill to be shared with other employees. A different first step could be to identify the natural leaders among your frontline staff and include them in early WPW training, with the explicit expectation that they put this knowledge to use with their residents and fellow staff members.

Dying well is not a "program." It is an inherent part of living well, and an integral part of excellence in caregiving. Creating the culture in which living well and dying well "is just what we do here" is the ultimate goal.

Assemble an Able Leadership Team

The organizational transition requires a team of effective, mission-driven leaders with a clear WPW vision. Optimally, this includes representatives at all levels and from all departments. Start with your staff members who already "get it" and support their teaching the next most-inclined group as a second step. Many people learn a subject more thoroughly when they know they will be expected to mentor coworkers and new employees.

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Find the Right Employees

Our think tank considered this the most crucial measure in developing true WPW in end-of-life care. Reconfiguring your advertisements, interview process, trainings, and performance reviews will help you select and develop a cadre of employees who focus on strengths.

Develop Intentional Training Programs

Providing adequate tools to committed employees is pivotal, often best done from an outcome-based thinking approach: what do we want service to look like, and what will we have to do to get there from here?

You may find you need to change the balance of your training, from 90% clinical and 10% psychosocial to much more psychosocial, with a strengths-based emphasis and psychosocial training of all staff members. Some organizations may need to increase frontline staffing to enable sanctioned time for WPW activities with residents. Other tactics include learning circles in which caregivers share and learn palliative-caregiving techniques from one another, or teaching staff how to meet psychosocial and clinical needs at the same time.

Reward WPW Behavior

It is essential to provide an environment where whole-person caregiving can flourish. Techniques that contribute to such an environment include, first, following a WPW path in your own life. It is futile to teach whole-person caregiving to employees, unless they themselves are treated as whole persons with unique strengths, gifts, and needs (including those for personal wellness). Other techniques include ensuring that you and your organization know each individual staff member; revising policies and procedures to reflect WPW; developing job descriptions and performance evaluations that reward a WPW focus on strengths; and encouraging more genuine involvement between direct care staff and residents. Above all, recognize and communicate that the emphasis on a "good ending," one ending at a time, is a commitment by the entire organization.

Enlist the Support of the Wider Community

One of the first essential steps is making sure that your philosophy around palliative care is shared by your medical director and medical staff. We also recommend working proactively with surveyors, hospice organizations, and other related organizations to keep them apprised of your objectives and planed changes. Equally important is the development of a strategy for educating diverse stakeholders—families and friends of residents, your governing body, and the community at large, including churches, nursing schools, and colleges.

Welcome the Inevitable Challenges of this Transition

Any major change within a person or an organization brings uncertainties and errors along the way. Transitioning to a WPW approach to palliative care is no different. Managers may have different ideas about how to proceed, and you may lose some staff who cannot make the transition. There is considerable upfront cost in time and energy to rework personnel and administrative procedures. Discipline yourself to welcome each mis-step in the developmental process as an opportunity to improve your process. An abundance of "learning opportunities" is one of the differences between trail blazing and taking the well-trodden path.

Sustained focus on providing end-of-life care within a WPW environment is rich with rewards. With time this commitment will have an increasingly positive impact on your employees' job satisfaction and—thanks to the most effective of all marketing techniques, word of mouth—your occupancy rate. The highest reward, however, is intrinsic—knowing that you and your organization are achieving excellence in a partnership with people, one person at a time, at one of the most important and sacred times of their lives. ALC

> **If this were your own death, how would you want it?**

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Nutrition Therapy for C. *Difficile* Diarrhea

(continued from page 13)

may be used to manage diarrhea and constipation. "Research suggests that FOS may have a role in prevention and treatment of *C. difficile* infections by helping to restore normal indigenous microflora."[7] ALC

Becky Dorner, RD, LD, is a speaker and author who provides education, publications, presentations, and consulting services to enhance the quality of care for our nation's older adults. Visit www.BeckyDorner.com for free articles, information, publications, CEU programs, and teleseminars, and to sign up for a free monthly e-mail magazine.

Table 1. Resources

- *Clostridium difficile* Support Group: www.cdiffsupport.com
- Infectious Disease Fact Sheet (*Clostridium difficile*). Environmental Health and Safety Division of the Washington University in St. Louis: www.ehs.wustl.edu
- Medline Plus, National Library of Medicine, National Institutes of Health, Medical Encyclopedia: Stool *C. difficile toxin*: www.nlm.nih.gov/medlineplus/ency/article/003590.htm.
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