

# Beloit Regional Hospice

*Supporting the Spirit of Life*

*A publication for physicians and other health care providers*



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*At Beloit Regional Hospice, our mission is to help make each moment of remaining life as full and comfortable as possible.*

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## Physicians Urged to Ensure Access to Hospice for an Often 'Invisible' Population

Nursing homes are the permanent site of care for more than 1.5 million adults in the U.S., and the site of death for approximately one-third of the population. Physicians play a pivotal role in helping this often "invisible" and vulnerable population receive needed palliative and end-of-life care, according to an article published in the *Journal of the American Medical Association*.

**"Given the stark reality that 30% of Americans will die in nursing homes and that more than half of nursing home residents will die within six months of admission, providing hospice or palliative care is essential."**

Hospice services "increase attention to pain management, improve communication with family members, and decrease hospitalization at the end of life," according to the authors. Hence, physicians are urged to individualize their care of seriously ill nursing home patients, communicate prognosis, and document preferences for advance care planning.

Prognosis in a nursing home patient is determined mainly by medical condition and functional status, note the authors. The proportion of nursing home residents with four or more impairments in activities of daily living has risen from 35% in 1999 to a current 50%. Besides being seriously ill, socially isolated, and often cognitively impaired, many residents have difficulty finding a personal physician who will care for them through the course of their illness.

"Most nursing home residents are cared for by family physicians, general internists, and geriatricians who work part-time in the

nursing home," write the authors. If a patient's physician does not plan to be the attending physician of record in the nursing home, he or she should arrange for an effective hand-off to an accepting physician, they urge.

Although 65% of nursing home residents have some form of advance directive, advance care planning is a continuous process, requiring ongoing discussion as prognosis and preferences change, state the authors. "Although one might think that this process is only the responsibility of the primary care physician, often cardiologists, oncologists, pulmonologists, neurologists, or other physicians caring for patients with advanced life-limiting diseases have the opportunity and responsibility to discuss life planning with their patients."

"The nursing home is the last site of care for many disabled adults, yet it may be invisible to many who live in the community, as well as to office- and hospital-based health care professionals," the authors suggest. "Nursing home residents are one of the most vulnerable populations and an opportunity for physicians to meet their professional mission."

Resources for physicians interested in increasing proficiency in providing nursing home care are available online from the American Medical Directors Association at [www.amda.com](http://www.amda.com).

*Source: "The Physician's Role in Patients' Nursing Home Care," Journal of the American Medical Association; October 5, 2011; 306(13):1468-1478. Zweig SC, Popejoy LL, Parker-Oliver D, Meadows SE; Department of Family and Community Medicine, School of Medicine; and Interdisciplinary Center on Aging, University of Missouri, Columbia.*

# Time-Limited Trials Can Help Patients and Families Shift Focus to Hospice Care

In the care of seriously ill patients who may be nearing the end of life, physicians and families can be faced with the decision of whether or not to initiate disease-directed interventions in clinical circumstances in which the outcome is uncertain. A possible way forward in this challenging situation may be the use of a time-limited trial (TLT), according to an article recently published in the *Journal of the American Medical Association*.

A TLT “is an agreement between clinicians and a patient/family to use certain medical therapies over a defined

period to see if the patient improves or deteriorates according to agreed-on clinical outcomes,” write the authors. If the patient improves, the therapy can be continued. If the patient deteriorates, the therapy is withdrawn, and goals of care often shift to palliation and hospice care.

Although there is a lack of empirical evidence regarding the risks and benefits of TLTs, framing challenging medical decisions as TLTs can be helpful for both patients/families and the members of the medical team, the authors point out. [See sidebar, below.]

## BEFORE BEGINNING A TLT DISCUSSION WITH THE PATIENT/FAMILY:

- Assess the patient’s current prognosis, preferences, and clinical status, factoring in cognitive and functional status.
- Seek consensus among all treating clinicians regarding the patient’s medical status and treatment options.
- Select the main medical spokesperson and identify key clinicians to include.
- Determine whether the patient has done any advance care planning.
- Identify key patient and family decision makers, and encourage surrogates to use “substituted judgment” to represent the voice of an incapacitated loved one.
- Carefully weigh the benefits and burdens of the intervention and whether its effect can be determined within a set time.
- Identify clear clinical markers of improvement or deterioration.

### Framing Challenging Medical Decisions as Time-Limited Trials Can:

- Allow families to learn and observe how physicians are trying to balance the benefits and burdens of medical treatment honestly and compassionately with the patient and the patient’s family
- Help treating clinicians reach a consensus and speak with a unified voice
- Lessen potential conflict among medical teams and the patient/family by establishing mutual expectations and a regular, structured dialogue about the patient’s progress
- Provide a path to a middle ground between patients/families who want “everything” done and medical professionals who may want to unilaterally limit treatment

— Adapted from Quill and Holloway, *Journal of the American Medical Association*

## APPROACH TO A TLT FAMILY MEETING

1. Ask each person to identify him- or herself and to state how he or she relates to the patient.

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## Palliative Care Access Report Card: Nation’s Grade Improves to ‘B’

The rapid growth rate of palliative care teams in U.S. hospitals reflects considerable improvement in this country’s care of the seriously ill, according to an analysis of the survey responses of 2489 hospitals in the American Hospital Association database.

Prepared by the Center to Advance Palliative Care (CAPC) and the National Palliative Care Research Center as an update to its 2008 “Report Card,” the findings were published in the *Journal of Palliative Medicine*, and the full 40-page report has been released to Congress.

“Palliative care teams are transforming the care of serious illness in this country because they address the fragmentation of the health care system and put control and

choice back in the hands of the patient and family,” says co-author and CAPC director Diane E. Meier, MD. “Hospitals today recognize that palliative care is the key to delivering better quality, coordinated care to our sickest and most vulnerable patients.”

### KEY FINDINGS

- The number of hospitals with a palliative care team increased from 658 (24.5%) to 1568 (63.0%) from 2000 to 2009.
- The Northeast has the highest prevalence of palliative care teams (73% of hospitals with  $\geq 50$  beds), while the lowest prevalence is in the South (51% of hospitals with  $\geq 50$  beds).
- More than half of the 50 states received

a “B,” seven states plus the District of Columbia received an “A,” with only two states — Delaware and Mississippi — receiving a “D.”

According to CAPC, the steady growth in palliative care is a response both to the increasing number and needs of Americans living with serious illness, and “the overwhelming realities of caregiving faced by patients’ families.”

Source: “America’s Care of Serious Illness: A State-by-State Report Card on Access to Palliative Care in Our Nation’s Hospitals,” *Journal of Palliative Medicine*; Epub ahead of print; DOI: 10.1089/jpm.2011.9634. Morrison RS, Meier DE, Augustin R, Souvanna P; National Palliative Care Research Center, Center to Advance Palliative Care, Mount Sinai School of Medicine, New York City.

# Burdensome End-of-Life Transitions Found Common among Nursing Home Patients with Advanced Dementia

Nearly one in five nursing home residents with advanced cognitive impairment experiences burdensome — and often avoidable — transitions in health care settings near the end of life, with the rate of such transitions varying greatly by state, according to a report published in *The New England Journal of Medicine*.

“A total of 96% of family members report that comfort is the primary goal of care for their relatives with advanced dementia,” write the authors. “Yet as we found, the pattern of transitions among nursing home residents with advanced cognitive impairment is often inconsistent with that goal.”

Recurrent hospitalizations for conditions that are potentially manageable and predictable among advanced dementia patients can cause distress near the end of life, point out the authors. Sources of such distress include: the trauma of the physical transfer; increased confusion caused by unfamiliar surroundings and providers; inability of staff in the new setting to address the patient’s special needs; and lack of provider communication about goals of care.

Investigators analyzed national Medicare data on 474,829 functionally dependent nursing home residents with advanced dementia (mean age, 85.7 years) who died between 2000 and 2007. In a second analysis, hospital referral regions were ranked into quintiles based on the rates of burdensome transitions among nursing home residents who died in 2006 and 2007.

Burdensome transitions included any transfer in the last three days of life, lack of continuity in nursing homes before and after hospitalization during the last 90 days of life, and multiple hospitalizations in the 90 days before death.

## KEY FINDINGS

- Overall, 19% of residents had at least one burdensome transition in the last 90 days of life, with wide variation by region (range, 2.1% in Alaska to 37.5% in Louisiana).
- 11.6% had a health care transition in the last three days of life.
- The rate of one or more burdensome transitions increased nationally from 17.4% in 2000 to 19.6% in 2007.

## FACTORS ASSOCIATED WITH AN INCREASED RISK OF BURDENSOME TRANSITION:

- Lack of a do-not-hospitalize order (adjusted risk ratio, 2.14; 95% confidence interval [CI], 2.06 to 2.23)
- Lack of a do-not-resuscitate order (adjusted risk ratio, 1.63; CI, 1.61 to 1.65)
- Black race (adjusted risk ratio, 1.24; CI, 1.22 to 1.26) or Hispanic ethnicity (adjusted risk ratio, 1.24; CI, 1.21 to 1.27)
- Male sex (adjusted risk ratio, 1.20; CI, 1.18 to 1.22)
- Lack of a written advance directive (adjusted risk ratio, 1.15; CI, 1.14 to 1.17)

Quality of end-of-life care was found to vary greatly by hospital referral region. Nursing home residents in regions in the highest quintile of burdensome transitions in 2006 and 2007 were significantly more likely than those in the lowest quintile to experience care indicative of poor quality end-of-life care.

## RESIDENTS IN THE HIGHEST QUINTILE WERE MORE LIKELY TO:

- Have a feeding tube inserted in the last 90 days of life (adjusted risk ratio, 3.38; CI, 2.48 to 2.60)
- Spend time in an intensive care unit in the last 30 days of life (adjusted risk ratio, 2.10; CI, 1.93 to 2.29)
- Be enrolled in hospice within three days of death (adjusted risk ratio, 1.17; CI, 1.07 to 1.28)

“Burdensome transitions are common, vary according to state, and are associated with markers of poor quality in end-of-life care,” the authors conclude.

Source: “End-of-Life Transitions among Nursing Home Residents with Cognitive Issues,” *The New England Journal of Medicine*; September 29, 2011; 365(13):1212-1221. Gozalo P, Teno JM, et al; Department of Health Services, Policy, and Practice, Brown University, Providence, Rhode Island; Hebrew Senior Life, Institute for Aging Research, Boston; and Dartmouth Institute for Health Policy and Clinical Practice, Dartmouth Medical School, Lebanon, New Hampshire.

## Time-Limited Trials Can Help Patients

*Continued from Page 2*

2. Summarize the meeting’s purpose.
3. Ask the family members for their views of the patient’s situation.
4. Reconcile the understanding of the clinical team with the patient’s views.
5. Propose the key elements of the TLT.
6. Explain how progress will be measured and communicated. If possible, try to link clinical markers of improvement or deterioration to signs that would be visible to the patient and family.
7. Suggest a time frame for reevaluation, based on the patient’s clinical condition, the type of intervention, and the needs of the patient and family.

### 8. Schedule a follow-up meeting.

Arrangements should be made to inform the family on a regular basis about the patient’s progress, and potential actions to be taken at the end of the TLT should be defined. “These are not rigidly binding contracts,” write the authors, “but rather ways of structuring challenging decisions and linking them closely with what clinicians and families are observing about the patient’s condition.”

Source: “Time-Limited Trials Near the End of Life,” *Journal of the American Medical Association*; October 5, 2011; 306(13):1483-1484. Quill TE, Holloway R; Center for Ethics, Humanities, and Palliative Care, University of Rochester Medical Center, New York.

## Having an Advance Directive Does Not Decrease Survival in Patients with Low or Medium One-Year Risk of Death

Discussing an advance directive (AD) with a health care professional, or having an AD documented in the medical record does not affect survival in patients hospitalized for medical illness, report researchers from Colorado.

“We found no decrease in survival for patients at low and medium one-year risk of death who reported having discussed ADs or who had an AD in their medical record, providing important evidence that having advance care planning discussions does not hasten death in this group of adults,” write the authors of a report published in the *Journal of Hospital Medicine*.

The team analyzed data from the medical records, bedside interviews, and state Vital Records of 458 patients admitted to three Denver area hospitals for medical illness during a 17-month period beginning in 2004. Participants

were stratified into cohorts having low, medium, or high risk of death at one year, based on previously validated criteria for identifying patients for whom a palliative care intervention would be appropriate. The 356 patients with low or medium risk of death were followed for six years.

### KEY FINDINGS

- Overall, 45% of participants reported having an AD discussion with a health care professional.
- Only 10% of all patients had an AD documented in their medical record.
- During the six-year follow-up period, 26% of patients died.
- For those subjects with a low or medium risk of death at one year, having an AD discussion or documentation of an AD in the medical record did not affect survival.

“Our results underscore the importance

of educating the public on the importance of ADs,” comment the authors. “ADs allow patients to express preferences that incorporate both *quantity* and *quality* of life, as there are times when interventions at the end of life may increase length of life to the detriment of quality of life.”

Despite the stipulation by the Patient Self-Determination Act that all patients admitted to a health care facility receive counseling on ADs, less than half of the study subjects reported having such a discussion. Only 10% had completed an AD, leading the authors to conclude “that huge opportunities exist for improvement in advance care planning.”

*Source: “They’re Going to Unplug Grandma: Advance Directive Discussions and Documentation Do Not Decrease Survival in Patients at Baseline Lower Risk of Death,” Journal of Hospital Medicine; September 29, 2011; DOI: 10.1002/jhm.930. Fischer SM, et al; Department of Medicine, University of Colorado School of Medicine, Aurora.*



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