

# Quality of Life Matters®

News & clinical findings about serious illness

Vol. 20, Issue 2 Aug/Sept/Oct 2018

## Palliative Care Benefits Nursing Home Residents with Serious Illness Who Are Not Ready for Hospice

Palliative care (PC) consults have the potential to greatly benefit a broad group of seriously ill nursing home (NH) residents, and should not be thought of as appropriate care reserved only for persons nearing the end of life, urge the authors of a study published in the *Journal of Palliative Medicine*.

“Palliative care consults in U.S. nursing homes provide accessible PC expertise to residents with serious illness who may not yet qualify for or desire Medicare hospice,” write the authors. “NH residents who receive PC consults have the potential

to achieve the highest quality of life earlier in the trajectory of their serious illness.”

PC provides symptom control and supportive services similar to those of hospice — the gold standard of end-of-life palliative care — but a PC consult, although also ordered by a physician, does not require that the seriously ill patient forgo disease-modifying treatment or be documented as having a terminal prognosis. Disease-modifying treatment is currently covered under the Medicare skilled nursing facility (SNF) benefit, the authors note.

Investigators analyzed merged Medicare and NH data along with consult data from two hospice-affiliated entities providing PC to residents of 54 nursing homes in eight counties in RI and NC from 2008 to 2010. Residents who received PC consults (“recipients;” n = 875) were compared to a sample of the total of all residents (“prevalence sample;” n = 7477) regarding six-month survival following the time of initial consult.

Nurse practitioner PC specialists provided the consults under the supervision of certified palliative medicine physicians. Members of a team of interdisciplinary PC specialists visited the patients if and as their care was warranted.

The researchers also compared results for residents with short NH stays (< 90 days) vs those with long stays (≥ 90 days) in both groups. Those with short NH stays were usually patients who entered to receive rehabilitation or other skilled care

following hospitalization, the authors note.

### CONSULT RECIPIENT FINDINGS

- 4.2% of all NH residents had a PC consult, two-thirds of whom were those with short NH stays.
- The SNF Medicare benefit, which covers disease-modifying treatments, was in place for 81.1% of short-stay and 26.9% of long-stay consult recipients.
- One-half of short-stay and 57% of long-stay consult recipients were alive six months after the initial consults.
- Those who died within six months did so at median 33.5 days (short-stay) and 34.5 days (long-stay).
- At six months, about 60% of surviving short-stay consult recipients were living in the community with home health care, and about 5% with hospice; in contrast, only 22% of long-stay recipients were in the community with home health or hospice, while 59% resided in NHs with no hospice or SNF care.

“The high rates of SNF care and six-month survival among NH recipients of PC consults demonstrate the utility of these consults before Medicare hospice eligibility or use,” write the authors. “Consults have the potential, therefore, to reach many individuals with a serious illness who are not near the end of life.”

### SHORT-STAY COMPARISONS

- Short-stay consult recipients were more likely than short-stay residents gener-

### Inside:

#### NewsLine..... 1–3

- ✓ Palliative Care Benefits Nursing Home Residents with Serious Illness Who Are Not Ready for Hospice
- ✓ Over One-Fourth of Men with Advanced Prostate Cancer Receive High Rate of Testing Despite Lack of Benefits

#### Research Monitor..... 4–5

- ✓ Older Americans More Likely to Die at Home or in the Community Than in Acute Care Facilities
- ✓ Crucial for Positive Care Transitions: Compassion, Continuity, and Accountability

#### Clinician Resources..... 6–7

- ✓ Five Strategies Identified to Help Cancer Patients Avoid Preventable Acute Care
- ✓ Dementia-Specific Directive Addresses Changing Preferences as Disease Advances

Continued on Page 3

# NEWSLINE

## Over One-Fourth of Men with Advanced Prostate Cancer Receive High Rate of Testing Despite Lack of Benefits

Increased monitoring for disease progression among men with metastatic prostate cancer (mPCa) significantly raises healthcare costs while failing to demonstrate improvement in either survival or quality of care at the end of life, according to a report published in *Cancer*, a journal of the American Cancer Society.

“Aggressive monitoring is a likely harbinger of aggressive treatment,” write the authors, “which often is associated with delayed referral to palliative or hospice care, which are key components of comprehensive management in patients with advanced malignancies.”

Further, in addition to increased costs incurred over the last year of life and no improvement in end-of-life care quality, intensive disease monitoring may have other negative patient impacts, such as “increased anxiety and time lost from work or family, as well as increased radiation exposure,” the authors note.

Investigators analyzed data from the linked Surveillance, Epidemiology, and End Results (SEER)-Medicare database from 2004 through 2012 for men newly diagnosed with Stage IV metastatic prostate cancer who survived six months or more following diagnosis (n = 3026).

“Extreme users” were those who, over a six-month period, had either received serum prostate-specific antigen (PSA) testing more than once per month or undergone cross-sectional imaging or bone scans more frequently than once every two months.

### OVERALL

- 26.1% of subjects were identified as extreme users.
- Extreme users were more likely than their counterparts to be younger ( $P < 0.001$ ), white/non-Hispanic ( $P <$

*“The importance of the early initiation of hospice and palliative care cannot be overstated, because it may improve quality of life as well as ease the burden of expenditures at the end of life.”*

— Golan et al, *Cancer*

0.001), married ( $P = 0.006$ ), higher earning ( $P < 0.001$ ), more educated ( $P < 0.001$ ), and less likely to reside in the South and more likely to live in the West ( $P < 0.001$ ).

- Extreme users visited the medical oncologist more frequently in a six-month period than did non-extreme users (8 vs 2 visits;  $P < 0.001$ ), whereas both groups visited a urologist a median of three times during a six-month period.

### KEY FINDINGS

- Receipt of chemotherapy within six months of diagnosis with mPCa was associated with a higher likelihood of extreme use (odds ratio [OR], 1.45; 95% confidence interval [CI], 1.23 to 1.7;  $P < 0.001$ ); in contrast, receipt of androgen deprivation therapy within six months was protective of extreme use (OR, 0.82; 95% CI, 0.71 to 0.94;  $P = 0.006$ ).
- More frequent oncology office visits were associated with a higher likelihood of extreme use (OR, 1.18; 95% CI, 1.16 to 1.21;  $P < 0.001$ ).
- Medical costs following diagnosis were 36.4% higher per year among extreme users than among non-extreme users

(95% CI, 27.4% to 45.3%;  $P < 0.001$ ).

- Costs in the last year of life were 35.1% higher among extreme users (95% CI, 20.2% to 50.0%;  $P < 0.001$ ).

“The association between increased imaging and PSA testing and increased costs is not surprising, because patients and physicians who monitor disease progression more intensely also are likely to pursue more aggressive and potentially costly treatment,” comment the authors.

“Clinicians are encouraged to set expectations and develop treatment and disease monitoring plans that are in keeping with patient goals,” they continue. “Monitoring for disease progression outside of clinical trials should be reserved for those in whom findings will change management.”

### NO BENEFIT TO EXTREME DISEASE MONITORING

Extreme use was not associated with improved quality of care in the last month of life, as measured by timing of hospice referral, frequency of emergency department visits, hospital or ICU admissions, and length of stay. Although measurements showed slightly worse care quality for extreme users than for non-users, the differences were not statistically significant.

### QUALITY OF CARE INDICATORS, EXTREME USERS VS NON-EXTREME USERS

- >1 hospital admission in the last month of life (20.1% vs 16.7%)
- >1 emergency department visit in the final month (18.2% vs 15.7%)
- Hospital length of stay  $\geq 14$  days (13.8% vs 12.3%)

*Continued on Page 3*

# NEWSLINE

## Palliative Care Benefits Nursing Home Residents with Serious Illness Who Are Not Ready for Hospice (from Page 1)

ally to have cancer (22.0% vs 12.4%), COPD (37.4% vs 30.6%), or CHF (43.7% vs 37.9%), and to be in daily and intense pain (34.9% vs 19.2%).

- Short-stay recipients were also more likely to have unstable conditions (79.5% vs 59.3%) and to have recently experienced an acute episode or flare-up (70.0% vs 53.1%).
- A terminal prognosis of  $\leq 6$  months to live was very low in both short-stay groups, although slightly higher among consult recipients (3.2% vs 1.7%).
- 81.1% of short-stay consult recipients were on Medicare SNF at baseline, compared with 56.3% of short-stay residents.

### LONG-STAY COMPARISONS

- Although there were fewer differences between groups among long-stay residents, those receiving a PC consult were more likely than long-stay residents generally to have COPD (34.4% vs 29.0%), recent weight loss (14.2% vs 10.0%), and daily pain (15.7% vs 6.4%).
- Long-stay PC recipients were also more likely to have unstable conditions (64.3% vs 47.6%) and a recent acute

flare-up (26.6% vs 16.3%).

- PC recipients with long stays were twice as likely to be on Medicare SNF at baseline (26.9% vs 13.1%).

### SHORT- VS LONG-STAY CONSULT RECIPIENTS

- Short-stay recipients had less cognitive impairment than did long-stay recipients (moderate, 25.4% vs 50.2%; severe, 6.2% vs 12.5%).
- Short-stay recipients had more cancer without dementia (22.0% vs 6.2%) and more daily pain (34.9% vs 15.7%).
- Consult recipients with short stays were more likely to have unstable conditions (79.5% vs 64.3%) and recent acute episodes (70.0% vs 26.6%) than were long-stay recipients.
- 81.1% of short-stay consult recipients were on Medicare SNF at their initial consult compared with 26.9% of long-stay recipients.
- Six-month survival rates did not differ significantly between short- and long-stay consult recipients ( $P < 0.05$ ).

“To our knowledge, this is the first study to describe and longitudinally follow a cohort of NH residents after initial receipt

of their PC consults,” note the authors. They hope it will be “an important first step” in understanding characteristics and outcomes of those who use PC consults in NHs, which may help in the development of guidelines for PC consult referral.

### PC ACCESS IN NURSING HOMES OF ‘CRITICAL’ IMPORTANCE

In a second study of PC access, a research team found that, although 69% of residents in three California NHs were eligible for formal PC and 71% of these reported high symptom burden, not one was receiving PC specialty services or under the care of a geriatric specialist.

Further, symptom burden reported by PC-eligible residents was consistently higher than that perceived by their families, with 64.3% of families vs 70.6% of residents indicating the presence of bothersome symptoms “usually or always” in the past week, and 60.7% of families vs 82.3% of residents reporting “severe or very severe” symptoms.

“Increasing access to PC for NH residents is critical, given mounting evidence confirming that PC care in the NH setting is associated with improved care quality and satisfaction, enhanced symptom management, and fewer emergency department visits, particularly when such care is initiated earlier in the disease course,” write the authors of a research letter published in *JAMA Internal Medicine*.

Source: “Palliative Care Consults in U.S. Nursing Homes: Not Just for the Dying,” *Journal of Palliative Medicine*; February 2018; 21(2):188–193. Lima JC, Miller SC; Department of Health Services, Policy and Practice, Center for Gerontology and Health Care Research, Brown University School of Public Health, Providence, Rhode Island. “Palliative Care Eligibility, Symptom Burden, and Quality-of-Life Ratings in Nursing Home Residents,” *JAMA Internal Medicine*; January 1, 2018; 178(1):141–142. Stephens CE et al; Department of Community Health Systems, University of California, San Francisco.

## Prostate Cancer (from Page 2)

- ICU admission within one month of death (26.2% vs 22.7%)
- Hospice referral within six months of death (21.5% vs 20.3%)
- Hospice referral within the last month of life (15.0% vs 12.8%)
- Hospice referral within the final week of life (4.5% vs 3.3%)

“Overall, the rates of hospice use were less than 25%, suggesting an area for further improvement,” note the authors. “The importance of the early

initiation of hospice and palliative care cannot be overstated, because it may improve quality of life as well as ease the burden of expenditures at the end of life.”

Source: “Increased Resource Use in Men with Metastatic Prostate Cancer Does Not Result in Improved Survival or Quality of Care at the End of Life,” *Cancer*; Epub ahead of print, March 26, 2018; DOI: 10.1002/cncr.31297. Golan R et al; Department of Urology, Weill Cornell Medical College-New York Presbyterian Hospital; and Department of Healthcare Policy and Research, Weill Cornell Medical College, New York City.

# RESEARCH MONITOR

## Older Americans More Likely to Die at Home or in the Community Than in Acute Care Facilities

Trends in end-of-life care from 2000 to 2015 show that beneficiaries of Medicare fee-for-service (FFS) coverage are less likely to die in acute care hospitals and more likely to die in a home or community setting, but slightly more likely to be admitted to an ICU in the last month of life, according to the results of a large retrospective study reported in *JAMA*.

Investigators analyzed Medicare administration data on a 20% random sample of 1,361,870 decedents who had Medicare FFS (mean age, 82.8 years; female, 58.7%) in 2000, 2005, 2009, 2011, and 2015, and a 100% sample of 871,845 decedents who had a Medicare Advantage Plan (mean age, 82.1 years; female, 54.0%) in 2011 and 2015.

### SITE OF CARE, PLACE OF DEATH

- From 2000 to 2015, the proportion of deaths occurring in acute care hospitals steadily decreased, from 32.6% to 19.8%.
- Deaths in a home or community setting (including assisted living facilities) increased during the same period, from 30.7% to 40.1%.
- ICU use during the last 30 days of life increased from 24.3% in 2000 to 29.2% in 2009, where it stabilized at about 29.0% through 2015.
- Potentially burdensome healthcare transitions during the last three days of life increased from 10.3% in 2000 to a high of 14.2% in 2009, then decreased in 2015 to 10.8%.
- Hospice services saw continued growth in use by patients at the time of death, from 21.6% in 2000 to 50.4% in 2015.
- Referral to hospice within three days of death increased from 4.6% in 2000 to 9.8% in 2009, then declined to 7.7% in 2015.

Nursing homes remained the site of death for about one-quarter (24.9% in 2015) of beneficiaries throughout the study period, and nursing home stays within 90 days of death were relatively stable, at 43.5% in 2015.

### OTHER BURDENSOME PATTERNS OF CARE

- Hospitalization during the last 90 days of life rose to a high of 69.3% in 2009, then decreased slightly to 65.2% in 2015.
- Multiple ( $\geq 3$ ) hospitalizations in the last 90 days of life declined from a high of 11.5% in 2009 to 7.1% in 2015.
- Two or more hospitalizations for infections or dehydration during the last 120 days of life also declined during that period, from a 2009 high of 16.7% to 12.2% in 2015.
- Healthcare transitions in the last three days of life increased from 10.3% in 2000 to 14.2% in 2009, then declined to 10.8% in 2015.
- Transitions from nursing home to hospital reached a mean high of 0.58 transitions per patient in 2009, then declined to 0.33 transitions per patient in 2015.
- There was a slight decline in the proportion of patients spending  $\geq 4$  days on a mechanical ventilator during a terminal hospitalization, from 3.1% in 2000 and 3.2% in 2009 to 2.5% in 2015.

### MEDICARE ADVANTAGE

Patterns of care similar to those of FFS patients were observed among Medicare Advantage beneficiaries in the rates for sites of death, place of care, and health care transitions near the end of life. However, Medicare Advantage patients were less likely than FFS patients to be hospitalized and more likely to die at home or in a

community setting rather than in a nursing home. The proportion of decedents who were enrolled in Medicare Advantage during the last 90 days of life increased from 22.6% (n = 358,600) in 2011 to 29.9% (n = 513,245) in 2015.

The period covered by this study was a time of sweeping changes in U.S. medical care for seriously and terminally ill patients. Hospice services were expanding rapidly, and a new medical specialty, hospice and palliative medicine, was formally recognized. U.S. hospitals initiated and greatly increased the presence of palliative care teams, and new quality-of-care and readmission rules were enforced with the enactment of the Affordable Care Act in 2010.

Yet, the improvements in end-of-life care found in their study show a broad trend that cannot be clearly ascribed to any of these possible contributing factors, the authors warn. "It is difficult to attribute the observed changes to any single intervention or policy designed to improve care at the end of life," they write.

Nevertheless, since "death in the ICU is seldom viewed as a good death," the authors express cautious optimism that "[e]ven though individuals may differ in their preferences regarding location of death, the ongoing trend toward stabilization of ICU use is an important marker of improvement."

*Source: "Site of Death, Place of Care, and Health Care Transitions among U.S. Medicare Beneficiaries, 2000–2015," JAMA: Journal of the American Medical Association; Epub ahead of print, June 25, 2018; DOI: 10.1001/jama.2018.8981. Teno JM, Gozalo P, Trivedi AN, Bunker J, Lima J, Ogarek J, Mor V; Division of General Internal Medicine and Geriatrics, Oregon Health & Science University, Portland; Department of Health Services, Policy, and Practice, School of Public Health, Brown University; and Providence VA Medical Center, both in Providence, Rhode Island.*

# RESEARCH MONITOR

## Crucial for Positive Care Transitions: Compassion, Continuity, and Accountability

For a safe and manageable healthcare transition, patients and their caregivers value compassionate communication, care continuity, and health system accountability during and after a hospital discharge, but report feeling fearful and abandoned when their transition experiences seem unsupported, according to a report published in *Annals of Family Medicine*.

“Our study is the most comprehensive examination to date of the patient and caregiver care transition experience,” write the authors. Their findings suggest that “clear accountability, care continuity, and caring attitudes are essential” during a care transition. The potential benefits of a positive transition experience are considerable, they note, and include “patient satisfaction, caregiver self-confidence, and better adherence to care plans.”

Investigators analyzed interview and focus group responses of 248 patients and caregivers who had experienced a care transition from hospital to private home or nursing home within the past 90 days in 2015 and early 2016. Participants were recruited from six healthcare networks in six U.S. geographic regions as the pilot study for the Project ACHIEVE (Achieving Patient-Centered Care and Optimized Health in Care Transitions by Evaluating the Value of Evidence), a planned national survey to determine the most effective transition services from the perspective of patients and their caregivers.

### OVERALL

- Patient participants were mean age, 61.2 years; female, 57%; and non-Hispanic white, 49%.
- Caregiver participants were mean age, 55.7 years; female, 84%; and non-Hispanic white, 48%.
- Over three-quarters (75.2%) of patient participants had  $\geq 3$  chronic conditions.
- 44% of patients and 24% of caregivers

had low health literacy.

- 29% of patients and 15% of caregivers screened positive for depressive symptoms.

### OUTCOMES IMPORTANT TO PATIENTS AND CAREGIVERS

**Feeling cared for and cared about.** “Participants unanimously expressed a wish for health professionals to sincerely convey their concern for, and commitment to, the patient’s recovery and caregiver’s well-being,” write the authors. Simple gestures such as calling them by name and sitting down while talking to them indicate empathy and patience, and can foster trust and lead to better care plan adherence.

When participants did not feel supported and cared about, caregivers felt distressed and unprepared to carry out the care plan, and patients felt as though they were an inconvenience, expressing “doubt and mistrust” of those upon whose medical expertise their stable health and survival depended.

**Unambiguous accountability from the healthcare system.** Participants wished to know which member of the healthcare team was responsible for their care, and to whom they could turn at any time for medical care or advice. A sense of accountability “provided needed reassurance and cultivated trust,” note the authors. Participants who did not perceive provider accountability described feeling uncertain, anxious, and alone.

**Feeling capable of executing the care plan.** Participants who felt prepared for the implementation of care on their own after discharge reported increased self-confidence and trust in providers, and said they were better able to adhere to the care plan. Participants, especially caregivers, who did not feel prepared reported feeling stressed and worried about causing harm.

### HOW PROVIDERS CAN HELP

**Anticipating care needs.** Participants desired that care providers anticipate services and resources they might need following discharge, such as medications, supplies, transportation, and home care aids. Participants reported feeling helpless when they perceived that providers did not consider or anticipate their needs.

**Collaborative discharge planning.** Patients and caregivers considered it crucial that they be involved in the planning of the hospital discharge, and felt supported by clinicians who included them in the decision-making process. When excluded, they believed that their needs and preferences had been disregarded.

**Providing actionable information.** When care providers gave participants “tailored and easily understood” information and supervised training for clinical tasks, participants felt prepared and capable. A reported lack of actionable information and helpful training made caregivers feel stressed, deserted, and overwhelmed.

**Uninterrupted care.** Participants desired fewer handoffs, preferring to receive seamless care from providers who were familiar with them. “[C]ontinuity in care cultivated a sense of being known as a person and created greater confidence, engagement, and trust in the medical care,” write the authors.

“Health systems must learn how to better prepare patients and caregivers for care at home and design accessible channels for ongoing support in order to ensure the journey from hospital to home is safe, and supports each person’s recovery.”

*Source: “Care Transitions From Patient and Caregiver Perspectives,” Annals of Family Medicine; May 16, 2018; 16(3):225–231. Mitchell SE, Laurens V, Jack BW, et al; Department of Family Medicine, Boston Medical Center/Boston University School of Medicine, Boston.*

# CLINICIAN RESOURCES

## Five Strategies Identified to Help Cancer Patients Avoid Preventable Acute Care

Based on a review of best practices and supporting evidence, researchers from the University of Pennsylvania have proposed five best strategies for reducing cancer patients' unplanned emergency department (ED) visits and hospitalizations, according to a report published in the *Journal of Clinical Oncology*.

Research shows that more than half of advanced cancer patients who present to the ED are subsequently admitted to the hospital, often during normal clinic hours, note the authors. The most common reasons that cancer patients make these unplanned ED visits are fever, pain, dehydration, and abdominal and respiratory concerns.

In addition, more than one-quarter of patients undergoing cancer treatment are readmitted within 30 days. "Many episodes of unplanned acute care are likely preventable, with perceived rates of preventable hospitalization varying from 19% to 50%," the authors write.

Unplanned acute care for cancer patients is a major driver of unnecessary healthcare utilization and costs, costs that continue to rise yearly, the authors point out. To curb this trend, the Centers for Medicare and Medicaid plans to release a new rule assessing the quality of care for patients receiving chemotherapy. This rule is expected to affect hospitals' outpatient Medicare payments beginning in 2020.

To identify best practices for reducing cancer patients' unplanned acute care, the researchers conducted a search for articles published in the medical literature between 2000 and 2017, examined quality guidelines published by professional healthcare organizations, and evaluated current care delivery models. Five strategies were identified.

### STRATEGIES FOR REDUCING UNPLANNED ACUTE CARE

**1) Identifying patients at high risk for preventable acute care** enables oncology practices to provide interventions, resources, and support to those most in need. Examples of interventions include informal monitoring and the nascent techniques of risk-stratification models and predictive analytic techniques.

Because there are few such tools specific to patients with cancer, the authors hope they will be more broadly developed, with studies conducted to evaluate their effect on acute care. "Importantly," write the authors, "these models are designed to complement, rather than substitute for, physician involvement and discretion."

**2) Enhancing access and care coordination**, so that patients get the care they need when they need it, can include such elements as providing a clear and reliable way for patients to contact their care team — before or instead of presenting to an ED; improving and standardizing care transitions; and implementing navigator programs, in which clinicians or non-clinicians act as liaisons between patients and physicians and connect them with needed resources.

"Regardless of the methodology used, the importance of clear lines of communication cannot be overemphasized," comment the authors.

**3) Standardizing clinical pathways for symptom management** helps ensure that patients receive optimal treatment for those symptoms that may otherwise send them to the ED. Examples of interventions include acute symptom management and phone triage systems; incorporation of supportive care into disease management pathways; and ED symptom management pathways.

**4) Developing new loci and tactics for urgent care** can help prevent patients who need to be seen urgently from presenting to the ED, or, if they do, from being automatically hospitalized. Examples of interventions include embedded urgent care clinics; cancer clinicians embedded in the ED; dedicated acute cancer treatment clinics and observation units; and dedicated cancer EDs.

**5) Employing early palliative care** has been shown to improve quality of life, and "data regarding the ability of early palliative care to reduce all types of unplanned acute care are robust," write the authors. Although the use of palliative care in oncology practice continues to increase, it is often initiated late, rather than early, in the disease course.

Examples of strategies for early palliative care include standardized teaching in symptom management, as well as in goals-of-care and end-of-life discussions; standardized and automated guidelines for inpatient and outpatient consultation; embedded outpatient palliative clinics; and integrated inpatient palliative care/oncology units.

In an article they wrote for the general public, which was published in *The Philadelphia Inquirer*, the authors comment, "This isn't just about reducing unnecessary hospitalizations — it's about listening to our patients, trying to foresee their needs, and making what is inevitably a difficult period a little more tolerable."

*Source: "Best Practices for Reducing Unplanned Acute Care for Patients with Cancer," Journal of Clinical Oncology; May 2018; 14(5):306–313. Handley NR, Schuchter LM, Bekelman JE; University of Pennsylvania, Philadelphia. "Five Proven Ways to Help Save Cancer Patients from Preventable ER Visits," The Philadelphia Inquirer; April 24, 2018; Handley et al; University of Pennsylvania, Philadelphia.*

# CLINICIAN RESOURCES

A FREE ONLINE PATIENT RESOURCE: DEMENTIA-DIRECTIVE.ORG

## Dementia-Specific Directive Addresses Changing Preferences as Disease Advances

The Dementia Directive, a brief and practical supplement to a standard advance directive document, has been developed by a general internist for patients to provide guidance in decision making for families and proxies throughout the future stages of their possible Alzheimer's disease or other type of dementia.

Because dementia is "a unique disease from the standpoint of advance directives," the concise, five-page directive addresses the changing goals of care patients envision for themselves over the 5-to-20-year time frame of diminishing cognitive ability, explains Barak Gaster, MD, University of Washington, Seattle, who worked with experts in geriatrics, neurology, and palliative care to develop the directive.

"Primary care clinicians frequently encounter patients who are concerned about what would happen if they developed dementia," writes Gaster in an article published in *JAMA*. "Many such patients most likely would welcome having an opportunity to provide guidance about their care should dementia occur."

The online directive is available free of charge at [dementia-directive.org](http://dementia-directive.org) for patients to download and print. Clinicians are welcome to print copies to use as handouts for patients aged 65 years or older during their Medicare annual wellness exam, for example, and then to enter the returned, completed form into the patient's medical record.

The document includes two pages describing the experience of worsening dementia, and the compelling reasons for filling out a dementia-specific directive that addresses changes in preferences as the disease progresses.

Completing and sharing such a directive can provide patients with the assurance that their care preferences have been documented, families/surrogates with the comfort of knowing they're better prepared to make future decisions that represent their loved ones' wishes, and clinicians with guidance for providing care that aligns with patients' stated preferences.

The three-page directive itself covers goals-of-care preferences for each of the three stages of dementia: mild, moderate, and severe. Each stage of dementia is briefly described, in clear and easy-to-understand language. The same four options for acceptable medical interventions are presented in a checklist under each stage and explained.

### GOAL-ORIENTED OPTIONS INCLUDE:

- All possible life-prolonging efforts
- Life-prolonging treatments, but excluding resuscitation and ventilation
- Care that can be delivered at the place called "home" only; no resuscitation, hospitalization, or ED visits
- Comfort-oriented care only, to relieve suffering

Source: "Advance Directives for Dementia: Meeting a Unique Challenge," *JAMA*; December 12, 2017; 318(22):2175-2176. Gaster B, Larsen EB, Curtis JR; University of Washington, Seattle; Kaiser Permanente Washington Health Research Institute, Seattle; Cambia Palliative Care Center of Excellence, University of Washington, Seattle.

## End-of-Life Care Websites

American Academy of Hospice and Palliative Medicine  
[www.aahpm.org](http://www.aahpm.org)

American Hospice Foundation  
[www.americanhospice.org](http://www.americanhospice.org)

Information and Support for End-of-Life Care from the National Hospice and Palliative Care Organization  
[www.caringinfo.org](http://www.caringinfo.org)

Center to Advance Palliative Care  
[www.capc.org](http://www.capc.org)

The EPEC Project (Education in Palliative and End-of-Life Care)  
[www.epec.net](http://www.epec.net)

Palliative Care Fast Facts and Concepts, a clinician resource from the Palliative Care Network of Wisconsin  
[www.mypcnow.org/fast-facts](http://www.mypcnow.org/fast-facts)

Hospice and Palliative Nurses Association  
[www.hpna.org](http://www.hpna.org)

Hospice Foundation of America  
[www.hospicefoundation.org](http://www.hospicefoundation.org)

Medical College of Wisconsin Palliative Care Program  
[www.mcw.edu/palliativecare.htm](http://www.mcw.edu/palliativecare.htm)

National Hospice & Palliative Care Organization  
[www.nhpc.org](http://www.nhpc.org)

Division of Palliative Care  
Mount Sinai Beth Israel  
[www.stoppain.org](http://www.stoppain.org)

Promoting Excellence in End-of-Life Care  
[www.promotingexcellence.org](http://www.promotingexcellence.org)

**Quality of Life Matters®** is a registered trademark of Quality of Life Publishing Co.

© 2018 by Quality of Life Publishing Co. All rights reserved. No part of this newsletter may be reproduced without prior permission of the publisher.

For reprint requests or questions, contact 877-513-0099, info@QOLpublishing.com.

# End-of-Life Care Meetings for Clinicians

**National Hospice and Palliative Care Organization Interdisciplinary Conference 2018.** November 5–7, 2018, Hyatt Regency New Orleans, New Orleans, LA. Website: [www.nhpco.org/IDC2018](http://www.nhpco.org/IDC2018)

**Center to Advance Palliative Care National Seminar 2018: Practical Tools for Making Change.** November 8–10, 2018, Rosen Centre Hotel, Orlando, FL. CME/CEUs for physicians, nurses, and social workers. Website: [www.capc.org/seminar/](http://www.capc.org/seminar/)

**Global Pain Clinician Summit 2018: Transforming How We Care for People with Pain.** November 9–10, 2018, Joseph B. Martin Conference Center at Harvard Medical Center, Boston, MA. Inaugural global summit of the Academy of Integrative Pain Management (formerly the American Academy of Pain Management). Accredited for physicians, nurses, and other clinicians. Website: [www.integrativepainmanagement.org/page/annualmeeting](http://www.integrativepainmanagement.org/page/annualmeeting)

**Palliative and Supportive Care in Oncology Symposium.** November 16–17, 2018, Hilton San Diego Bayfront, San Diego, CA. Cosponsors: the American Academy of Hospice and Palliative Medicine, the American Society of Clinical Oncology, the American Society for Radiation Oncology, and the Multinational Association of Supportive Care in Cancer. Website: [pallonc.org](http://pallonc.org)

**Current Topics in Primary Care and Palliative Care.** March 16–21, 2019, 5-Night Havana and Cozumel cruise conference, round trip from Fort Lauderdale, FL. Accredited by the Accreditation Council for Continuing Medical Education. Phone: 800-422-0711; Website: [www.continuingeducation.net](http://www.continuingeducation.net)



**HOSPICE**  
OF SANTA CRUZ COUNTY

*Your choice. Your journey.*

Hospice of Santa Cruz County is committed to providing physicians with quality end-of-life information. This newsletter is recommended by the American Academy of Hospice and Palliative Medicine. We hope you find it useful.

Our responsiveness and around-the-clock availability can support physicians and ensure expert end-of-life care for your patients – 24 hours a day, every day. Call 430-3000 to make a referral, request a family information visit, or consult with one of our medical directors. Visit our useful website for physicians at [www.hospicesantacruz.org](http://www.hospicesantacruz.org).

Phone: 831 430 3000 • [www.hospicesantacruz.org](http://www.hospicesantacruz.org)  
940 Disc Drive, Scotts Valley, CA 95066

## Quality of Life Matters®

Now in its 20th year of publication, **Quality of Life Matters®** is recommended as an educational resource by the American Academy of Hospice and Palliative Medicine.

The periodical is dedicated solely to news and clinical findings related to serious illness, and is researched and written by professional medical journalists specializing in covering palliative care issues.

It is an independent publication; it is not affiliated with any healthcare organization or company other than the publisher. The quarterly newsletter is published by Quality of Life Publishing Co., a firm dedicated to assisting clinicians in easing the way for patients with serious illness and their families.

We customize copies of the newsletter for healthcare organizations to provide as an educational service for their clinicians.

For information, rates, or reprint requests for this and other publications, please contact Quality of Life Publishing Co.

TOLL FREE  
**1-877-513-0099**

EMAIL  
[info@QOLpublishing.com](mailto:info@QOLpublishing.com)

MAIL  
Quality of Life Publishing Co.  
6210 Shirley St., Ste. 112, Naples, FL 34109

**EXPLORE OUR FULL LINE OF  
BRANDED EDUCATIONAL MATERIALS  
at [www.QOLpublishing.com](http://www.QOLpublishing.com)**

- Tools to meet HIS/CMS & CAHPS® requirements
- Written to meet health literacy standards
- Available in multiple languages



### EDITORIAL TEAM

**Karla Wheeler**  
Editor-in-Chief & Founder

**Jan Carlton Doetsch**  
Clinical Editor

**Gretchen Landolt**  
Chief Executive Officer

**Kelly Brachle**  
Chief Operating Officer

**Mike Schadler**  
Production Manager

**Tony Uricchio**  
Graphic Designer

**Jenny Wheeler**  
Assistant Editor

**Mary Kay Grimaldi**  
Editorial Consultant