
IDAHO END-OF-LIFE NEWS

Formerly Hospice News Idaho

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A Service of the *Idaho End-of-Life Coalition*

Formerly A Better Way Coalition, Inc., and the Idaho State Hospice and Palliative Care Organization

To submit news or events or to subscribe, please email IdELC@clearwire.net

IDAHO END-OF-LIFE COALITION UNITES STATE EFFORTS

The Idaho State Hospice and Palliative Care Organization and A Better Way Coalition, Inc., formally united operations on December 9 to become the Idaho End-of-Life Coalition (IdELC). Cheryl Simpson-Whitaker, MSW, founder and long-time leader of ABWC, serves as Board chair; Carolyn Nystrom, RN, long-time Idaho hospice leader, serves as vice-chair; and Jonathan Krutz, MBA, serves as CEO. IdELC remains the voice of hospice in Idaho as part of a broader mission to improve the experience and minimize the negative impacts of the end-of-life across Idaho.

Your support and involvement for 2009 are needed.

Find more information and your IdELC membership form at www.hospiceidaho.org.

Idaho End-of-Life Events Calendar *all times MT*

Educational Events

- Feb 12-13 **NHPCO Manager Development Program**, Vancouver, WA
Details at www.wshpco.org/cde.cfm?event=234411; contact anne@wshpco.org
- July 20-22 **Dying Well in Idaho Conference**, Boise Centre on the Grove / Grove Hotel
Part of the collaborative Annual Convention of Idaho's Nursing Home, Assisted Living, Hospice and Home Health organizations
Keynote speakers: Ira Byock, MD; NHPCO CEO Don Schumacher, PhD
Contact: Jonathan Krutz at IdELC@clearwire.net

Find other Idaho healthcare educational events at www.idahoahcec.org/calendar

Meetings and Other Events: To join IdELC mtgs by phone, call 712-432-1100, enter 300176#

- Mon, Feb 9 **Education Committee**, by phone, 10-noon
2nd Mon/m Contact: Teresa Dixon, RN, CHPN, chair, at trsdixon@yahoo.com
- Tue, Feb 17 **Public Policy (frmly Adv Care Plng) Com**, Saint Als, Boise or by phone, 4-5:30
3rd Tue/m Contact: Jill Anderson, CNS, chair, at jillande@sarmc.org
- Wed, Feb 18 **Community Engagement Committee**, by phone, 1-2:30 p.m.
3rd Wed/m Contact: Heidi Walker, chair, at heidi@thevisionsgroup.org
- Thu, Feb 19 **Hospice Policy Committee**, St. Luke's Hospice (or by phone, 9:30-11:30 a.m.)
3rd Thu/m Contact: Mary Lou Long, RN, MSN, chair, at longm@slrmc.org
- Tue, Mar 3 **Hospice Quality Partners Call**, 3-4 p.m.
1st Tue/m Component: Clinical Excellence and Safety (see www.nhpc.org/quality)
Contact: Sarah Bradbury, MBA Sarah@xlhospice.com
- Sat, Apr 18 **IELC Board of Directors Retreat**, Sun Valley (tentative)
quarterly Contact: Cheryl Simpson-Whitaker, MSW, chair, at cksw46@msn.com
- Thu, Apr 16 **National Healthcare Decisions Day 2009**
Info at: www.nationalhealthcaredecisionsday.org

Idaho News

IDAHO ALZHEIMER'S TASK FORCE PROPOSED

On January 15, Senator Gary Schroeder introduced the Idaho Alzheimer's Disease Strategic Plan Task Force Act as Senate Bill 1001 in the Idaho Senate. The bill would create a task force to:

- Identify the emotional and financial impact of Alzheimer's disease and related dementias
- Assess the needs of those living with Alzheimer's disease and related dementias
- Develop comprehensive strategies to address the needs identified and assessed

Alzheimer's and other dementias are the looming end-of-life crisis in America. Alzheimer's is the fifth leading cause of death among those age 65 or older. Deaths from cancer, heart disease and stroke have all grown at a rate less than the growth of Idaho's population over the past twelve years, but deaths from Alzheimer's have doubled, according to Idaho Department of Health and Welfare vital statistics data reported at the 2008 Dying Well in Idaho Conference.

The Act is supported by the Alzheimer's Association chapters in northern and southern Idaho and spearheaded by Skeeter Lynch, LMSW, who says, "There are no paid lobbyist to advocate for this bill. It is a citizen driven bill that asks for Idaho to work collaboratively towards the common goal of supporting the well-being of Idaho citizens living and dying with Alzheimer's disease and related dementias, and those who care for them."

Lynch discussed the bill and strategies to encourage its passage with the IdELC Public Policy Committee on January 27. The bill is being considered for hearing by the Senate Health and Welfare Committee, chaired by Senator Patti Ann Lodge. Find an information sheet about the proposal at www.hospiceidaho.org under "What's New." Read the bill and find contact information for your state senator at www.legislature.idaho.gov/senate. Contact Lynch at stratpath@moscow.com.

MEDICAID HOSPICE PROGRAM SEEKS PROVIDER INPUT

Hospice personnel involved in billing, and other interested staff, are invited to a teleconference with representatives from Medicaid to discuss proposed changes in requirements. Topics for discussion will be Election/ Recertification documents, and timelines for submitting paperwork and claims. Medicaid's nurse reviewer and program manager are inviting feedback and discussion before proposed changes are finalized. Please join us on Thursday, 2/12, from 10:00-11:00am, so your voice is heard and questions are answered.

Medicaid staff have met twice with the IdELC Hospice Policy Committee to discuss the proposed changes and now seek wider input from the hospice community.

To access the conference call dial 846-8863 local or 1-800-575-8877 toll free. You will be prompted to enter Participant Number 381. Also, please refer to the Hospice website at: <http://www.medunit.dhw.idaho.gov/> for the Teleconference Agenda listing changes under consideration. Please call Jan at 364-1818 if you have questions about this discussion.

ACCESS/SHARE NON-ENGLISH END-OF-LIFE MATERIALS

The IdELC Quality/Research Committee is seeking end-of-life materials in foreign languages to make available in Idaho. Some end-of-life materials in Spanish can already be found at www.abetterwaycoalition.org. Click on “New Spanish Resources available through NHPCO.” Spanish-language materials include Idaho’s Living Will and Health Care Power of Attorney form and the related wallet card. A link under “Resources in Spanish” will take you to the Spanish and Mandarin Chinese resources available through Caring Connections of the National Hospice and Palliative Care Organization. These include materials on advance care planning, hospice, and grief. If you are aware of similar kinds information in other languages on other websites, or if you have files you would be willing to share through IdELC, please contact IdELC@clearwire.net so we can make them available in Idaho through our website.

HOSPICE CAP AFFECTS FOUR IDAHO HOSPICES

Only four Idaho hospices had their reimbursements limited by the Medicare hospice cap in 2006 reported National Government Services (NGS), Idaho’s Medicare fiscal intermediary for hospice, at their January 13 meeting with state hospice organizations.

The cap limits reimbursements to a hospice to no more than about \$23,000 on average per hospice patient each year. Since the patient mix for most hospices includes one third or more who are referred only within the last week of their life, the cap is generally a non-issue. But hospices with fewer short-stay patients and more focus on care for Alzheimer’s or other terminal conditions for which prognoses are difficult can find their average reimbursements per patient exceeding Medicare cap levels.

IDAHO MEDIA COVERAGE OF END-OF-LIFE ISSUES

Recent Idaho media coverage of end-of-life issues includes:

- 12/29/08 “Reviewing End Of Life Issues,” Don Wimberly interviews IdELC CEO Jonathan Krutz, Idaho Public Radio:
http://www.publicbroadcasting.net/idaho/news.newsmain?action=article&ARTICLE_ID=1449390
- 12/27/08 “Hospice changes end-of-life experiences,” Idaho Press Tribune:
<http://www.idahopress.com?id=2715>
- 11/23/08 “Have that talk about end-of-life wishes,” Idaho Statesman, by Diane Ronayne:
<http://www.idahostatesman.com/life/story/580880.html>

Please contact IdELC@clearwire.net with Idaho end-of-life media coverage you see.

CONGRESS PROPOSES DELAY IN HOSPICE CUT

Effective October 2, the Bush administration cut funding for hospice by stripping a budget neutrality factor from the Medicare reimbursement calculations for hospice. This move led to an outcry from the hospice community, which Medicare’s advisory body, MedPAC, reports operates on lower margins than almost any other health provider. As a result, Congressman Charlie Rangel, chairman of the House Ways and Means Committee, proposed and

the House of Representatives approved inclusion of the following language in the recent House-passed economic stimulus bill: “For Fiscal Year 2009, the Secretary of Health and Human Services shall not phase out or eliminate the budget neutrality adjustment factor in the Medicare hospice wage index before October 1, 2009, and the Secretary shall recompute and apply the final Medicare hospice wage index for fiscal year 2009 as if there had been no reduction in the budget neutrality adjustment factor.” The debate now shifts to the Senate.

FREE 7th ANNUAL CANCER SURVIVORSHIP SERIES BEGINS APRIL 14

On Tuesday, April 14th, CancerCare will present the first of a three-part telephone education workshop program, The Seventh Annual Cancer Survivorship Series: Living With, Through & Beyond Cancer. This free series, made possible by support from National Cancer Institute and Lance Armstrong Foundation, offers cancer survivors, their families, friends and health care professionals practical information to help them cope with concerns and issues that arise after treatment ends.

Part I, which takes place on April 14th is entitled, Managing the Stress of Survivorship. The faculty for this program includes Keith M. Bellizzi, PhD, MPH, Cancer Survivor, Assistant Professor, Human Development and Family Studies, University of Connecticut; David Spiegel, MD, Wilson Professor in the School of Medicine, Associate Chair, Department of Psychiatry and Behavioral Sciences, Stanford University School of Medicine; and Guadalupe R. Palos, RN, LMSW, DrPH, Instructor, Clinical Research Faculty, Assistant Professor, Division of Internal Medicine, Department of Symptom Research, The University of Texas MD Anderson Cancer Center.

Part II, The Importance of Nutrition and Physical Activity, will take place on May 19th. Part III, Survivors Too: Family, Friends and Loved Ones: Managing the Fatigue of Caregiving, will take place on June 23rd. All of the of the workshops take place from 1:30 to 2:30 pm Eastern Time. These workshops are free and no phone charges apply; however, pre-registration is required. To register simply go to the CancerCare website, www.cancercare.org/TEW.

National News

“TERMINAL UNCERTAINTY” QUESTIONS SIX-MONTH PROGNOSIS

A recent *Seattle Weekly* article, “Terminal Uncertainty,” examines the Washington and Oregon “Death With Dignity” laws in light of the difficulty of making an accurate six-months’ prognosis about the length of someone’s life. The author cites the experience of Maryanne Clayton, who was diagnosed with metastatic lung cancer and given two to four months to live four years ago. Her participation in clinical trials of two new drugs have proved that her original prognosis was “quite wrong.”

Doctors in Washington are divided about the new law. Some say that they will refuse to help patients die, and others say, “It’s the most humane thing to do.” One thing both groups can agree on is a statement by Dr. Stuart Farber, palliative care head at the University of Washington Medical Center, who says, “Our ability to predict what happens to you in the next six months sucks.”

The six-month rule is based on the Medicare hospice benefit requirement that patients be certified as having a six-month or less prognosis. For Medicare, says the article, doctors must “fill out a detailed checklist derived from Medicare guidelines that are intended to ensure that patients truly are at death’s door... The checklist covers a patient’s ability to speak, walk, and smile, in addition to technical criteria specific to a person’s medical condition, such as distant metastases in the case of cancer or a ‘CD4 count’ of less than 25 cells in the case of AIDS.” In Oregon, and probably in Washington, doctors are only asked to check a box on a form that indicates that the patient has six months or less to live. No questions are asked about how that was determined.

But even when doctors use the hospice eligibility criteria, it’s often wrong. One study has found that 17% of patients outlive their hospice eligibility, with another saying 13%. Prognostication does have a scientific basis. Populations of people with specific conditions have been followed and the lengths of their lives noted. But that means that the life expectancy for medical conditions found in textbooks is a “statistical average,” and some will do better and some worse.

In other cases, patients are dying of chronic diseases which may be stable, but occasionally have acute exacerbations. According to the article, “The problem for prognosis is that doctors have no way of knowing when those attacks will be or whether patients will be able to survive them.” The percentage of patients outliving a six-month prognosis with pulmonary disease, heart failure and severe liver disease is far higher than in a Nicholas Christakis study – a 1999 paper published in *JAMA* found that 70% of 900 patients eligible for hospice with those diseases lived longer than six months.

Christakis, author of *Death Foretold: Prophecy and Prognosis in Medical Care*, found that doctors make more accurate prognoses about patients they don’t know well, which suggests “that doctors who get attached to their patients are reluctant to talk of their imminent demise.” Brian Wicks, president of the Washington State Medical Association, says that oncologists are often cheerleaders “right up to the end.”

In Washington, J. Randall Curtis, director of an end-of-life research program at Harborview Medical Center, says that the inability to arrive at an accurate prognosis is one reason he’s not comfortable with physician-assisted suicide. He says it’s one thing when a six-month prognosis entitles a patient to hospice services, and quite another when it enables patients to kill themselves. According to Curtis, “The consequences of being wrong are pretty different.”

Providence Hospital of Seattle, a Catholic institution, will not participate in the new law. Medical director Wayne McCormick says he’s preparing a speech for patients who ask about the law: “I will stop at nothing to ensure that you’re comfortable. I won’t shorten your life, but I will make it as high-quality as possible.” On the other hand, Thomas Preston, medical director of Compassion & Choices of Washington, says his speech will go like this: “You have to understand that this prognosis could be wrong. You may have more than six months to live. You may be cutting off some useful life.” Preston says he will advise doctors to take a more conservative approach than the law does, and to wait until a patient has only a couple of months to live before writing a prescription.

At the University of Washington, Farber doesn't yet know whether he'll write lethal prescriptions, but he will refer patients to doctors who will. He thinks it's better to adhere to the "spirit of the law," so that he can say to someone who is near the end of life, "You're really sick and you're not going to get better."

At the other end of the spectrum, some patients want to die before they've reached the point of a six-month prognosis. Only patients who are terminally ill are eligible for lethal prescriptions in either Washington or Oregon, which leaves patients with extremely painful chronic conditions outside the law. Former Washington governor Booth Gardner, who pushed widely for his state's law, has Parkinson's disease, and would have preferred that the law apply to anyone who wanted to end their suffering regardless of life expectancy. **Researchers have found that fear of future suffering is a bigger factor than pain in influencing a decision to ask for a lethal prescriptions, as is a desire to control one's own death.**

Maryanne Clayton, in spite of having outlived her original prognosis by four years in good enough health to enjoy vacations with her children, still voted for the Death With Dignity Act. She asks, "Why force me to suffer?" and says that if she were in as much pain as she was when she was first diagnosed, she might take advantage of the law. (*Seattle Weekly*, 1/14)

PHYSICIAN EXPLORES THE NATURE OF DEATH IN MODERN HEALTHCARE

Craig Bowron, a hospital-based internist and writer in St. Paul, Minnesota, examines the "drawn-out indignities of the American way of death" in a recent article in *The Washington Post*. Bowron treats hospitalized adults of all ages and with all sorts of diseases. "Taking care of the threadworn elderly, those facing an eternal winter with no green in sight," says Bowron, is definitely the most difficult thing I do."

That, he writes, is "because never before in history has it been so hard to fulfill our final earthly task: dying. It used to be that people were 'visited' by death. With nothing to fight it, we simply accepted it and grieved. Today, thanks to myriad medications and interventions that have been created to improve our health and prolong our lives, dying has become a difficult and often excruciatingly slow process."

Bowron relates the stories of several of his patients, including an 85-year-old diabetic woman suffering from the "dwindles" of advanced age and illness. She's exhausted and weak, miserable from the dialysis she undergoes, and she won't chew and swallow unless reminded. But her family has requested a "full code" even though the chances of success are minimal. A 91-year-old man with mild dementia weeps in pain from his arthritis. An 86-year-old woman was transferred from a nursing home because the staff thought she might have pneumonia, in spite of her and her son's stated wishes that she not be resuscitated.

Bowron writes, "Nothing in my medical training qualifies me to judge what kind of life is satisfying or worth living. ... Patients can and do make enormous efforts and fight precipitous odds to get back to life as they knew it, or even just to go on living. But the difference for many elderly is that what's waiting for them at the end of this illness is just another illness, and another struggle."

He adds, “To be clear: Everyone dies. There are no life-saving medications, only life-prolonging ones. To say that anyone chooses to die is, in most situations, a misstatement of the facts. **But medical advances have created at least the facade of choice.** It appears as if death has made a counter-offer and that the responsibility is now ours. **In today’s world, an elderly person or their family must “choose,” for example, between dialysis and death, or a feeding tube and death.** Those can be very simple choices when you’re 40 and critically ill; they can be agonizing when you’re 80 and the bad days outnumber the good days two to one.”

Bowron writes of the conflict that the hospital staff experiences in these kinds of cases, the sense of doing something “to” a patient instead of “for” a patient. One physician told Bowron, “I feel like I am participating in something immoral.” Another questions, “Whatever happened to that ‘do no harm’ business?”

The article continues, “Everyone wants to grow old and die in his or her sleep, but the truth is that most of us will die in pieces. Most will be nibbled to death by piranhas, and the piranhas of senescence are wearing some very dull dentures. It can be a torturously slow process, with an undeniable end, and our instinct shouldn’t be to prolong it.”

Bowron concludes, “This isn’t about euthanasia. It’s not about spiraling health care costs. It’s about the gift of life — and death. It is about living life and death with dignity, and letting go. In the past, the facade of immortality was claimed by Egyptian kings, egomaniacal monarchs and run-of-the mill psychopaths. But democracy and modern medical advances have made the illusion accessible to everyone. We have to rid ourselves of this distinctly Western notion before our nation’s obesity epidemic and the surge of aging baby boomers combine to form a tsunami of infirmity that may well topple our hospital system and wash it out to sea. **At some point in life, the only thing worse than dying is being kept alive.”**

The article, “The Dying of the Light: The Drawn-Out Indignities of the American Way of Death,” can be found by searching www.washingtonpost.com for “Craig Bowron” (without the quotes). (*The Washington Post*, 1/11)

THE COLUMBUS DISPATCH OFFERS “DEATH PERCEPTIONS”

***The Columbus Dispatch* is offering a video series, “Death Perceptions,” which “examines death through the eyes of professionals who deal with it every day.”** Stories are told by a first responder, hospice nurse, state trooper, funeral director, youth pastor, child mortality expert, trauma surgeon, and others. Ohio death statistics from 2000-2006 can be searched on a number of demographics, including cause of death. The series is online at www.dispatch.com/death. (*The Columbus Dispatch*, 1/11)

MedPAC FINALIZES HOSPICE RECOMMENDATIONS AND HOSPICE ORGANIZATIONS REACH CONSENSUS RESPONSE

MedPAC commissioners met on January 9 and finalized their recommendations for changes to the Medicare hospice benefit, and will forward them to Congress in March. The

recommendations listed below are from the January 9 NHPCO Public Policy Alert, which says that they “are based on the initial draft voted upon by the Commissions and could slightly, but not substantively, change by the time the final version is released next week on the MedPAC web site.” **The final version will be released this week at www.medpac.gov.** **The recommendations include:**

- * **Changes to the payment schedule to reflect higher per diem payments at the beginning of a hospice enrollment, and lower payments per day as the length of stay increases;**

- * **A relatively higher payment for costs associated with patient death, and**

- * **Implementation of these payment changes in 2013, following a brief transition period.** Changes are to be implemented in a “budget neutral” manner during the first year.

Congress will be requested to direct the Secretary of Health and Human Services to:

- * **Require that patients be visited by a hospice physician or advanced practice nurse to recertify eligibility at the end of each 180 day period, and to “attest that such visit took place”;**

- * **Require a brief narrative of the clinical basis of a patient’s prognosis for all certifications and recertifications, and**

- * **Require that the medical director of the Medicare claims processing contractor review all hospice stays of more than 180 days if such stays make up at least 40% of the total cases of the hospice.**

The commissioners will also request that Congress direct the Office of Inspector General to investigate:

- * **Financial relations between hospices and long-term care facilities for conflicts of interest or where such relations may influence admissions to hospice;**

- * **Differences in patterns in the way nursing homes refer to hospice;**

- * **Whether hospices with unusual utilization patterns (such as a high number of very long or very short stays, or of patients who have been discharged from other hospices) have appropriate enrollment practices, and**

- * **Whether hospice marketing materials and admission practices are appropriate.**

NHPCO and the other hospice leadership organizations (American Academy of Hospice and Palliative Medicine, Hospice and Palliative Nurses Association, National Association for Home Care & Hospice, National Hospice Work Group, and Visiting Nurses Association of America) **issued a press release and their “Consensus Statement on Hospice Reform” on January 8** (see *HNN*, 1/6).

The consensus statement says, “Over the past several years, MedPAC has undertaken a review of the Medicare hospice benefit. While specific reforms and enhanced accountability measures are laudable and should be encouraged, those changes should be framed in the context of a comprehensive review of the various and complex components of end of life care and how the continuum of care can be expanded to increase access for patients and families. Included in this comprehensive review of hospice should be payment methodologies, fiscal constraints review, alternative eligibility criteria, and testing of new models of care, as well as any number of other issues.”

The statement suggests “several clear principles” which should guide such a review. These are:

- * “Advancing hospice and palliative care providers as the recognized providers of end of life care”;
- * “Preserving and enhancing the Medicare Hospice Benefit”;
- * “Recognizing high quality as the standard to which all providers must subscribe”;
- * “Ensuring accountability through transparency and fair regulatory scrutiny,” and
- * “Promoting increased access through expansion and collaboration.”

Regarding changes to payment systems, the group says, “As with any payment system, dramatic changes to the hospice benefit from established patterns of reimbursement are sure to produce displacements and unintended negative consequences. Given the nature of hospice referrals and the unique characteristics of the end of life patient demographics, unintended consequences of such changes are inherently difficult to predict. ... Payment reforms should be incremental, based on adequate data analysis, and need to be undertaken carefully, with effects on the patient and family in mind.”

Both the press release and the consensus statement are online at the NHPCO website at www.nhpc.org/i4a/pages/Index.cfm?pageID=5803. See www.medpac.gov/transcripts/20090109_Hospice_final_public.pdf for the outline distributed at the MedPAC meeting. (*NHPCO Public Policy Alert*, 1/9; *NHPCO Website*, 1/8; *PR Newswire*, 1/8)

2009 MEDICARE REFORMS TO “RUN THE GAMUT”

In “Medicare Reforms on Tap for 2008 [sic – should be 2009] Run the Gamut,” *Inside CMS* reports on talks with “a host of Washington insiders” about likely changes to the Medicare system in the next year.

Hospice leaders know that CMS will be collecting more data as part of its new quality/performance improvement focus. Janet Neigh, vice-president for hospice at the National Association for Home Care and Hospice, says that CMS will take the time to work with the hospice industry to figure out what should be reported, and how it should be done.

Neigh also says that **CMS will also train more surveyors.** The recent November training, coupled with another round in January and a possible one in March, and an upcoming satellite broadcast, help “give the industry hope that there will be a great deal of focus on data collection.” **This training push should help uncover any problems with the new CoPs so that CMS may refine them.**

Leaders in the hospice industry hope to persuade the Obama administration to restore the budget-neutrality adjustment factor in the hospice wage index. The industry also anticipates the continuation of the BNF debate in court. The author says, “Armed with affidavits from former CMS administrations declaring that it is something that should be included in the hospice reimbursement system, advocates will loudly proclaim that it was never meant to be a temporary addition to the benefit rate.”

Fiscal intermediaries may be asked to do more medical reviews, but their funding has not been increased, so Congress will have to supply money if that’s going to happen. **NHPCO’s**

Don Schumacher says that hospice programs are surveyed between seven and eleven years, and hospice advocates think that's too far apart. Problems can arise that go on for years, and HHAs and nursing homes are surveyed at least every other year.

Judy Lentz, executive director of the Hospice and Palliative Nurses Association, expects a revised edition of clinical guidelines for quality palliative care. Lentz says, "Palliative care is increasingly seen as cost-effective," and would like for CMS to "see us in palliative care as part of the answer, not part of the problem."

Changes in home health are expected to provide one of the few cost savings measures for Medicare. The Independence at Home programs, which would coordinate the care of Medicare patients at home, could save \$14-\$15 billion per year.

Regarding Medicare Part A changes, value-based purchasing, "where CMS demands higher quality and more value for each Medicare dollar," will be on the agenda. Jayne Hart-Chambers, senior vice-president of strategic policy for the Federation of American Hospitals, says, "What form that is going to take, whether that's health reform or some kind of Medicare reconciliation," is up in the air.

The hospital industry has some concerns about HAC (hospital-acquired conditions) and POA (present on admission) policies. Hart-Chambers cites three HACs as inappropriate: 1) **Catheter-associated urinary tract infections**, because it is not always possible to know whether the infection began in a nursing home or in the inpatient setting; 2) **Clostridium difficile-associated disease (C-DIFF)** is "not a 100 percent preventable infection; and 3) **Regarding prevention of slips and falls in inpatient settings**, Hart-Chambers says, "We're certainly willing to work with the department ... but you can't prevent falls 100 percent of the time."

Blair Childs, senior vice-president of corporate communications at Premier Inc, expects the Obama administration to be "more responsive to concerns raised by stakeholders," but he doesn't see the adoption of HACs and POAs "slowing down."

The article cites one congressional source as expecting \$15-\$25 billion in the economic stimulus package for health information technology (HIT). Childs, however, expects "hard questions about privacy and security issues." It also says that the industry largely views the selection of Tom Dachsle as HHS secretary as "positive."

The author sees "no clear push for Part B reforms," but expects a continuing focus on the Physicians Quality Reporting Initiative. Experimentation with new methods and pilot projects to help determine new policies is expected. Insiders also do not expect Congress to allow the scheduled January, 2010 21% decrease in Medicare payments to take effect.

For Part C, Congress should consider MedPAC findings when it looks at Medicare Advantage payment reform. One attorney expects there to be "a big whack" at Medicare plan payments, and predicts that Congress will phase out subsidies over a number of years.

Insiders expect reforms to Part D, "including stepped up CMS oversight and imposition of a minimum rebate for drugs covered by prescription drug plans (PDPs) or

Medicare Advantage PDPs.” One source said that Congress will “get serious about cost containment,” and that the main target will be Medicare Advantage plans.

The long-term care industry is struggling with cuts in Medicaid funding, and leaders “vow to do whatever it takes in 2009 to warn states and the federal government not to shift more resources away from facility-based care, where patients can get 24-hour nursing care.” **The LTC industry is expected to support a bill which would “massively expand education and training programs aimed at geriatrics health care professionals,” and the Community Choice Act,** which lets “patients eligible for nursing homes or intermediate-care facilities for the mentally retarded ... choose a new option, ‘community-based attendant services and supports,’ that are based in home or community settings and include assistance with daily living and health-related functions.” (*Inside CMS*, 1/8)

PUBLIC POLICY NOTES

*** CMS has notified New York Medicaid officials that the income and assets of one spouse may not be protected if the other receives Medicaid and lives at home.** One state Health Department spokesman said, “They’re saying if you put your spouse in a nursing home, you’re going to get to keep more income than if you keep your spouse out of a nursing home. That’s completely opposite to public policy and research of the last 10 years.” The federal law, passed in 1988, “intended to protect healthy spouses with lower incomes and fewer independent assets from being reduced to poverty by their better-off spouses’ need for long-term care.” (*The New York Times*, 1/23)

*** In some states, Medicaid populations have grown by 5%-10% in the last year. Officials say that Medicaid enrollment lags job losses by several months, and the “growth in 2008 may represent only the leading edge of heightened demand.”** A nationwide survey by *The New York Times* found that social service agencies in some states are “overwhelmed,” and that state analysts have been forced to discard estimates that were only a few months old. Congressional Democrats are working on “a sizable increase in federal aid to state Medicaid programs as part of their economic stimulus package.” (*The New York Times*, 1/22)

*** Several consultants predict some difficulties for hospices with the new MAC (Medicare Administrative Contractor) structure. An *Eli’s Home Care Week* article says, “HHAs and hospices currently served by Palmetto GBA and National Government Services shouldn’t notice many changes,” but the National Association for Home Care & Hospice expects “major changes” for those served by Highmark Medicare Services and Noridian Administrative Services.** Tom Boyd, of Boyd & Nicholas, said that those with Palmetto GBA “should count their blessings ... none of the others have HHA and hospice experience.” Boyd also says that **chains will no longer be able to send all claims to one contractor, but will have to use the contractor in each geographic area.** (*Eli’s Home Care Week*, 1/16)

*** A news alert to NHPCO members said that the House of Representatives’ version of the nation’s economic stimulus plan retains the budget neutrality adjust factor for one year, retroactive to last October 1.** NHPCO and others will continue to work with Congress to

make sure that the Senate version also protects it, that both bills are passed, and that any differences are reconciled in a conference committee. (*NHPCO News Alert*, 1/16)

* **The IRS will use data from the new Form 990 “to determine if [tax exempt organizations] provide enough community benefits to remain tax-exempt.” An IRS spokesman also said that the agency may “overhaul” the community benefit standard.** (*The Bond Buyer*, 1/14)

* **CMS has selected Palmetto GBA to “process and pay all fee-for-service Medicare claims and perform related duties for South Carolina, North Carolina, Virginia and West Virginia,” which are known as MAC Jurisdiction 11.** Palmetto GBA will pay both Part A and Part B Medicare claims for those states, and will continue to process and pay hospice and home health agency claims to Medicare in 16 states. **Highmark Medicare Services has been chosen to process Medicare fee-for-service claims in Ohio and Kentucky, as well as home health and hospice claims in 15 states and the District of Columbia.** (*PR Newswire*, 1/9)

* **Robb Miller, executive director of Compassion & Choices in Washington state, expects “a very small number of people” to use the state’s new Death With Dignity Act, which takes effect March 5.** A February 10 hearing, held by the state Department of Health, will consider draft rules for the law’s implementation, “including reporting requirements for health care providers and the qualifications of witnesses for patients in long-term care facilities who make written requests for aid in dying.” Oregon’s law, after which the Washington law is modeled, has seen an average of 34 deaths per year in its first ten years, but observers expect that number to be 55 for 2008. (*The Seattle Post-Intelligencer*, 1/10)

* **The South Carolina House of Representatives has approved, 113-0, a resolution which would force the Department of Health and Human Services to restore the money cut from the state’s Medicaid hospice program.** The bill will now go to the Senate. (*AP State & Local Wire*, 1/16)

* **Florida’s newspapers continue to cover the anticipated effects of the loss of Medicaid hospice coverage in the state.** A letter to the editor of the *Tallahassee Democrat* urged legislators “to consider and adopt alternatives — other than neglecting our state’s most vulnerable population — to resolve this current budget crisis. Solutions abound; raise the state sales tax by one cent. An increase in the state sales tax would be spread across all individuals who use Florida’s resources, including tourists. Start collecting the tax on Internet sales.” (*Santa Rosa Press-Gazette*, 1/13; *Key West Citizen*, 1/8; *Tallahassee Democrat*, 1/11)

RESEARCH & RESOURCE NOTES

* **A recent study from the University of Wisconsin, published in the *Journal of Palliative Medicine*, examined hospice enrollment rates and the “sociodemographic and clinical predictors of hospice utilization” in patients who died within 30 days of a stroke.** The factors which predicted increased enrollment in hospice were “older age, female gender, health management organization (HMO) membership, length of stay more than 3 days, and dementia.” Factors associated with decreased enrollment included “African American race, mechanical ventilation, gastrostomy tube placement, uncomplicated diabetes mellitus, and

valvular disease.” The authors conclude, “Although overall enrollment rates were higher than anticipated, there remain important sociodemographic and clinical characteristics unique to this population that predict low hospice utilization that should serve as targets for further research and intervention.” (*MD Week*, 1/23; *Journal of Palliative Medicine*, 2008;11(9):1249-1257)

* **Researchers from the University of Maryland studied the services offered by hospice and mixed hospice/home care agencies. They found that “nonmixed agencies were significantly more likely than mixed agencies to provide many types of services.”** Services reported in the article abstract were volunteers, social services, spiritual care, bereavement care, counseling, and physician services. The authors conclude, “Mixed agencies provide a narrower range of services to hospice patients than nonmixed agencies, including fewer services considered cornerstones of hospice treatment.” (*Medical Care*, 2009;47(1):9-14)

* **The Lance Armstrong Foundation has granted a Montana State University nursing professor nearly \$107,000 to study the needs of dying patients on the Blackfoot Reservation.** Yoshiko Colclough and a team of community members will “interview the chronically ill, people who have lost family members to chronic illness and those who have cared for the chronically ill to learn about cultural values that could influence end-of-life issues in the community.” Colclough notes that most Indian Health Service hospitals focus on acute care and lack services for those who are chronically ill and dying. (*Montana’s News Station.com*, 1/20)

* **CMS recently announced that the Home Health, Hospice & DME Open Door Forum which was originally scheduled for January 22 will be rescheduled in mid-February.** (*CMS Email List*, 1/22)

* **A new study from the Hebrew SeniorLife’s Institute for Aging Research says that Alzheimer’s disease is not often cited on death certificates, and may be under-reported as a cause of death.** Thirty-seven percent of the death certificates of 323 patients with Alzheimer’s or other advanced dementia did not have dementia recorded on their death certificates. See www.alzinfo.org for more information. (*JAMA*, 2008;300:2608-2610; *Fisher Center for Alzheimer’s Research Foundation Website*, 1/12)

* ***Pain in Children: A Practical Guide for Primary Care* is reviewed in the current JAMA.** The reviewer says that this book “does an excellent job of highlighting the enormous effect pain can have on the child and the family. It emphasizes the pivotal role pediatricians and other primary care clinicians play in identifying, diagnosing, and managing pediatric pain.” (*JAMA*, 2009;301(2):220-221)

* **At 1:00 PM ET on January 22, CMS will air a 90-minute overview of the new hospice CoPs Part C.** The CMS Website says, “As a result of participating in the satellite broadcast the viewing audience will have a better understanding of the new conditions of participation and how to conduct a hospice survey using these new conditions.” Information on the program is online at surveyortraining.cms.hhs.gov/pubs/satellite.aspx. After January 22, the program will be available as an archived Webcast at surveyortraining.cms.hhs.gov. (*CMS Website*)

* **“Home Sick: When the Burden Of Care Falls on the Family,”** in a recent *Wall Street Journal*, explores the difficulties of bringing a hospitalized patient home. Bonnie Lawrence, of San Francisco’s Family Caregiver Alliance, says families often get little

warning or instruction. “ We’re discharging your father in two hours and we hope you have a hospital bed at home,’ or ‘Here’s a list of home-health agencies -- go check them out,’ are typical scenarios, Lawrence says. The article, which contains tips for managing an early discharge, is online at online.wsj.com/article/SB123180365247775321.html. (*The Wall Street Journal*, 1/13)

HOSPICE NOTES

* **On January 1, the Iowa Hospice Organization changed its name to the Hospice and Palliative Care Association of Iowa.** The press release said, “The new name draws upon the many hospice care programs that have added palliative care to the range of care and services they provide.” (*Hospice & Palliative Care Association of Iowa Press Release*)

* **Hospice nurse Dean Nash, of Crossroads Hospice in Memphis, was profiled recently in *The Commercial Appeal*.** Nash, a former accountant, changed careers and went into nursing after his father died. But after several years as a critical care nurse, he said he couldn’t do it any more. “It made me physically ill to see how horrible it was for these patients,” Nash said. His mother, a Crossroads volunteer, suggested he try hospice nursing, and Nash thinks he’s found his niche. The article says, “He doesn’t carry the weight of the dead with him, but says they’ve taught him how to live. [He] tries to find meaning in each day. He doesn’t carry grudges. He tries to find in each day the one thing he hopes to give people. Peace.” (*The Commercial Appeal*, 1/17)

* **In Lawrence, Kansas, Carol Schmitt is a hospice team manager for the Douglas County Visiting Nurses Association, Rehabilitation and Hospice Care.** Schmitt says, “Birth and death are both part of life’s natural cycle,” and thinks “it’s a wonderful job and a great privilege to be part of people’s end-of-life journey.” Schmitt says she thinks a great deal about death, but doesn’t know “if it’s part of her nature or just the nature of her work.” She says, “When I try to imagine how I’d feel if my husband or son were dying, I know I’d be overwhelmed with sadness and grief, but I don’t think that sadness will ultimately determine my memory or feelings for them. Death alone doesn’t define the essence of someone.” (*Lawrence Journal-World & News*, 1/19)

OTHER NOTES

* **In a recent interview, Dr. Robert L. Martensen, author of *A Life Worth Living: A Doctor’s Reflections on Illness in a High-Tech Era*, said, “Most Americans die in hospitals or nursing homes, and neither is configured to take care of dying patients.** There’s little palliative care available, and often the payment structure of health insurance doesn’t support it.” **Martensen thinks “doctors should get comfortable with being realistic.”** “Right now, we say, ‘I can’t take away a person’s hope,’ as if doctors were bestowing life. You have to support those hopes that are realistic, not this fantasy land.” (*The New York Times*, 1/20)

* **In North Carolina, the Greenville Museum of Art will display the fabric and thread art of Deidre Scherer during the month of February.** Two series of Scherer’s work that focus on end-of-life experiences, “Surrounded by Family and Friends” and “The Last Year,” will be included. (*The Daily Reflector*, 1/18)

* **An article in *The Washington Post* discusses the costs of reforming US health care. “We are on a collision course between our wish to live longer, healthier lives and our capacity to pay for that wish.** Whether we can somehow avoid the collision is perhaps the most important domestic issue of this century. From now on, health care costs will be up there with globalization, terrorism and climate change as a force shaping our world.” See www.washingtonpost.com/wp-dyn/content/discussion/2009/01/09/DI2009010902981.html for the full article. (*The Washington Post*, 1/12)

* **After theologian R. J. Neuhaus died, columnist David Brooks wrote a column on Neuhaus’ thoughts about death. Brooks said, “While most people might use the science of life to demystify death, Neuhaus used death to mystify life.”** He cites Neuhaus, writing of a near-death experience that he had – “We are born to die. Not that death is the purpose of our being born, but we are born toward death, and in each of our lives the work of dying is already under way.” The article is online at www.nytimes.com. Search for “defense of death” (without the quotes). (*The New York Times*, 1/12)

* **Thanks to Dream Foundation, Jessica Keenan is going to have the wedding she wants, in spite of her stage 4 breast cancer.** Dream Foundation has been called the Make-A-Wish foundation for terminally ill adults. When Jessica’s chemotherapy treatments drained her wedding budget, the nurses at her oncology treatment center recommended she contact them. A Foundation spokesman said, “We’re a conduit. People are willing to help. They just need to know how and where.” (*CNN Website*, 1/16)

* **Terry Quell, president of the Connecticut Nurses Association, says that Connecticut will be one of the states “hardest hit by the nursing shortage.”** A report by the United States Health Resources and Services Administration expects a shortage of 11,000 nurses in the state by 2010, and twice that many by 2020. (*Connecticut Post Online*, 1/11)

* **Keith and Brooke Desserich published their journal of their daughter Elena’s terminal illness, *Notes Left Behind: 135 Days With Elena*.** They had written so that their younger daughter, Gracie, would have something to remember her big sister by. They’ve realized that the initial printing of 10,000 books will not be sufficient and they expect to order more after a “Good Morning, America” segment featuring the family. More information is available at www.thecurestartsnow.org/desserich. (*The Cincinnati Enquirer*, 12/14)

* **Western Pennsylvania’s Family Hospice and Palliative Care created a Learning Center for Spirituality “to promote the inclusion of spiritual care for those facing life threatening illness through teaching, dialogue, advocacy, and research.”** The Hospice also offers a clinical pastoral education program, accredited by the College of Pastoral Supervision & Psychotherapy, and offers organized conferences that are “specifically geared to the demands of clergy at this difficult time.” (*Western Pennsylvania Hospital News*, 12/2008)

* **Kim Beck-Frate is a mental health counselor for the Traumatic Loss Program, part of Florida’s Halifax Health Hospice of Volusia/Flagler.** Since 2005, she’s been involved in helping families cope with unexpected losses. The program, which is funded by fundraising activities and donations from the Hospice’s Hope Again Circle of Friends, is publicized by pamphlets given to families when police, staff from the attorney general’s office, or victims’ advocates respond to a traumatic death. (*Daytona Beach News Journal*, 1/12)

* **SouthernCare, Inc., a privately owned Alabama hospice, agreed to “pay \$24.7 million to settle allegations that it submitted false reimbursement claims to the government.”** “The government said an investigation showed the company, with nearly 100 locations that care for about 5,000 people daily, charged Medicare for hospice care for patients who didn’t qualify for it.” (*AP State & Local Wire*, 1/15)

* **VITAS Innovative Hospice Care donated \$10,000 to cover the travel costs of six Tuskegee airmen and a companion for each to Barack Obama’s inauguration on January 20.** An all-black Army Air Corps unit was organized in 1941, since many War Department leaders had earlier felt that black Americans “lacked the intelligence, courage and patriotism to fly in combat.” The nearly 1,000 black pilots trained at Tuskegee Army Air Field “flew missions over Germany, Austria, Italy and North Africa, and had an impressive record of protecting bombers.” One of those who will attend, John Miles, had many hurtful words yelled at him, but on Tuesday, he says, they won’t matter. “I am a living witness,” he said, “I’m proud to be part of a group that struck a blow to discrimination.” (*San Antonio Express News*, 1/11)

* **A survey from the Association for Healthcare Philanthropy found that “eight percent of hospital fundraising executives who expect to raise less money this year than in 2008 said their institutions would have to curtail critical health care services for the poor and underinsured.”** Most AHP members who responded to the survey said “they will continue to provide vital community services, which range from free mammography and cancer screenings for the poor to community clinics, hospice facilities and immunizations for the uninsured.” (*PR Newswire*, 1/5)

* **In Milwaukee, nursing recruiters “have been forced to get increasingly inventive.”** At one event, experienced nurses were given a \$50 gas card just for coming to an interview. One Michigan company rolled out a red carpet, provided free champagne, and had Chuck Woolery host a trivia contest with prizes that included a one-year 2009 SUV lease, dinners and hotel stays. Other contest prizes have included GPS systems, flat-screen TVs and \$1000 shopping sprees. (*AP State & Local Wire*, 1/5)

* Florida newspapers included a number of articles about the Medicaid hospice benefit cuts (see *HNN* 1/6). **In a special to the *St. Petersburg Times*, Dr. Howard Tuch, Robert Woods Johnson Health Policy Fellow with Hospice of the Florida Suncoast, calls Florida’s cut of the Medicaid hospice benefit wrong and costly.** Tuch cites a Florida Hospices and Palliative Care study, widely reported in other newspapers in the state, that found that “Florida will actually increase its spending on care for the state’s terminally ill if it eliminates its hospice benefit. The study concludes that most of the costs attributed to hospice would simply be shifted elsewhere in the Medicaid budget.” The new Halifax Health’s Southeast Volusia Hospice Care Center, scheduled to open this week, will face “significant challenges” from the cuts. (*St. Petersburg Times*, 1/4; *Tallahassee Democrat*, 1/4; *Florida Today*, 1/3; *Fort Myers News-Press*, 1/5; *Pensacola News Journal*, 1/5; *Daytona Beach News-Journal*, 1/9; *WCTV*, 1/5; *Winter Haven News Chief*, 12/25; *Palm Beach Post*, 1/8; *South Florida Sun Sentinel*, 1/9)

* ***The Providence Journal* profiled the work of Pamela Colleran, spiritual care coordinator of Home & Hospice Care of Rhode Island. Colleran is a former Buddhist nun who has done special study in interfaith chaplaincy.** She says, “It’s very profound, a very sacred time that we get to see these patients. They consistently, every single one of the people that I’ve ever met, have really touched me, have shared ... the deepest things with me that you

can imagine.” Colleran says that most terminal patients “accept what is happening,” and that 80%-90% “experience dreams or visions of people already gone waiting to welcome them.” (*The Providence Journal*, 1/11)

* **Long Island cardiologist Sandeep Juahar says that the “diagnostic intuition” of doctors – the ability to diagnose quickly from physical observation and examination – is “becoming rare in the current era of technological medicine.”** But just as it was once common for doctors to exhibit such inhibition, it is still not unusual for patients to have “a sixth sense about their own deaths.” Juahar describes two such situations, where patients announced their impending deaths when he did not think them sick enough to die. He encourages attention to such intuitions, saying, “They often hold the vital clue.” (*The New York Times*, 1/6)

* **The Salinas Visiting Nurse Association offers bereavement groups, and found that in the wake of the steep drop in the stock market in October, people “were grieving in anticipation of the uncertainty of things to come in the economy.”** VNA is considering offering a bereavement group that focuses “exclusively on the economy.” Joseph Lumello, VNA bereavement coordinator, says that Kubler-Ross’s stages of grief are “applicable to any negative life change,” and that “her analysis would fit today’s free-falling economic realities and their impact on people.” (*The Californian*, 1/3)

* CMS has announced new contracts for Medicare Administrative Contractors (MACS). According to www.cms.gov, “The home health and hospice workload has also been split into four jurisdictions (see HH&H MAC Jurisdiction Map below). CMS is not going to procure separate MACs to service home health and hospice providers.” Go to <http://www.cms.hhs.gov/MedicareContractingReform/Downloads/HHMACJurisdictionFactSheets.pdf> to see more details. (www.cms.gov)

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