



## E-Newsletter

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### I/DD Hospice and Palliative Care Issues

*All of us at the Hospice and Palliative Care Association of NYS and NYSARC would like to wish a Happy and Healthy New Year to each of you!*

### In the News

Over the past several months, **The New York Times** has published several articles that examined the promises, challenges and costs of extending, *or ending*, the lives of terminally ill patients in a series called “[Months to Live.](#)” The series offers a number of thought provoking and informative articles as well as audio and video presentations. To take a look at all of the past articles and multi-media presentations in the series follow [this link.](#)

This month we are highlighting (below) two of the most recent articles in the series.

► **The New York Times article published December 23rd, 2009**, entitled ‘[Weighing Medical Costs of End-of-Life Care’ and Rethinking End-of-life Care](#)’, discusses one of the most difficult and controversial issues of the health care reform debate, weighing the cost benefit of medical procedures, tests and curative measures when the patient is considered too old or too ill to recover. This article focuses on the ‘high-intensity’ treatment practices of the U.C.L.A. Medical Center in Los Angeles, which has been ranked near the top of the list of hospitals that spend the most on end-of-life care without reporting better results than hospitals that spend much less. (These rankings were compiled by reports in [Dartmouth end-of-life analysis](#)) Nevertheless, the author reports several cases where patients who may have been considered too old or too ill for aggressive treatment at other facilities were evaluated at U.C.L.A. and treated successfully.

Dr. J. Thomas Rosenthal, the chief medical officer of the U.C.L.A. Health System, states that although “*his hospital has started re-examining its high-intensity approach to medicine, the more U.C.L.A.’s doctors study the issue, the more they recognize a difficult truth: It can be hard, sometimes impossible, to know which critically ill patients will benefit and which will not.*”

This is an interesting article that is thought provoking and of interest to end-of-life care providers. Follow this [link](#) to read the article in its entirety.

► **The New York Times article published on January 11, 2010**, entitled [Facing End-of-life Talks, Doctors Choose to Wait](#) which discusses the findings of a research article that was published in the January edition of the *Cancer Journal*. Dr. Nancy L. Keating, the first author of the study and an associate professor of medicine and health care policy at Harvard, stated that although her research team suspected that doctor/patient communication was falling short, *'the results came as a surprise: the doctors were even more reluctant to ask certain questions than the researchers had expected. Although 65 percent said they would talk about the prognosis "now," far fewer would discuss the other issues at the same time: resuscitation, 44 percent; hospice, 26 percent; site of death, 21 percent. Instead, most of the doctors said they would rather wait until the patients felt worse or there were no more cancer treatments to offer.'* The article reports that the result of waiting to discuss end-of-life options was that more *'dying patients may wind up in exactly in the situation they dreaded most, tethered to machines in a hospital instead of being kept comfortable at home in their own beds.'*

Although the NY Times article summarizes the journal article well, readers can access and review the actual study online at: ['Physician Factors Associated with Discussions about End-of-life Care.'](#)

The stipulations and regulatory reforms contained in the health care reform bills passed by both the House and the Senate have been watched closely by disability advocates; below are two articles recently published that discuss the impact this reform legislation may have for persons with a disability and for those who may care for them.

► An article published in the **Columbia Missourian** reports that the current bills hold promise for people with disabilities. The article specifically discusses how specific aspects of the health care bill would benefit the community, such as containing the cost of premiums, eliminating prohibition on pre-existing conditions and life-time caps on coverage as well as the addition of a public option. If you would like to read the entire article, use the link below.

[Health care reform bill holds promise for people with disabilities](#)

► **Disability Scoop** ([disabilityscoop.com](http://disabilityscoop.com)) is a nationally focused online news organization serving the developmental disability community including autism, cerebral palsy, Down syndrome, fragile-X and intellectual disability, among others. Every day 'Disability Scoop' sifts through the clutter of news to provide a central, reliable source of information and resources that take an in-depth look at what lies beyond the day's headlines, such as how health care reform will affect persons with disabilities. In November of 2009 they published an article titled, [Health Care Reform and People with Disabilities](#), which takes a closer look at how the 'health reform' legislation passed by the House of Representatives would impact persons with intellectual or developmental disabilities. The Congressional bill requires health insurers to offer more comprehensive coverage and to provide insurance to a wider swath of the population including those with pre-existing conditions. The measure would also create new long-term care options and expand Medicaid. Use the link above to read the article.

► On December 1st, 2009 the **New York Times** published a 'Personal Health' article by Jane Brody well worth reading, entitled, ['In Hospice, Care and Comfort as Life Wanes.'](#) In writing this article, the author spent a day in the company of hospice workers from the Visiting Nurse Service of New York (VNSNY), as they visited four different patients who were being cared for by hospice teams in their own homes. In the words of each individual patient, Jane shares with us all what having the hospice teams has meant to both the patient and their

families. This is a beautifully written, truly inspiring article that illustrates the benefit of the multidisciplinary, whole person model of care that hospice provides. As Jane Brody puts it, *“With each visit, the caring, patience, attention and expertise I observed left me wondering why all medicine is not like this -- focused on the whole person, not just a disease.”* If you would like to take the journey and read the article in its entirety, follow this [link](#).

### **Public Policy News / Advocacy Opportunities**

▶ **The Hospice Support Act of 2009 (H.R. 3831)**, which was recently introduced by Representative Jeff Fortenberry (R-Nebraska), would “amend the American Recovery and Reinvestment Hospice Support Act of 2009 to eliminate the phase out of the Medicare hospice budget neutrality adjustment.” The bill, which has been referred to the Ways and Means Committee, currently has no co-sponsors. If you would like to read the bill, follow its progress, alert other colleges or friends about it or contact your congressional representative regarding the bill, logon to [Washingtonwatch.com](http://Washingtonwatch.com).

▶ **A recent Manager’s Amendment to the Senate healthcare reform bill** has “a scaled down version of the cuts to hospice, similar to the proposal put forth by Senator Ron Wyden (D-OR) earlier this week. While the hospice community still faces significant reimbursement reductions through health reform, this development represents a necessary first step to minimizing the impact to patients and families before the cuts are enacted in 2013.” The alert encourages interested persons to contact their senators to let them know of their support of the amendment. (NHPCO Policy Alert, 12/19)

▶ **Hospice Advocacy Alert** - The House and Senate are actively working to reconcile both versions of the ‘Health Care Reform’ legislation so that a finalize bill will pass within the next couple of months, and among the many issues being discussed are a number changes that will impact end-of-life care. Because it is critical that members of Congress know what is at stake for the provision of Hospice in the future, all Hospice Advocates are urged to make sure that Congress knows where we stand. Use the following link to make your voice heard. [Take Action – Contact Your Representatives Today](#)

▶ **NHPCO** has also created a very useful and informative document that allows the viewer to read and compare the key ‘Health Reform Proposals’ from both the Senate and the House that impact end-of-life-care. You can view or print out this handy resource below:

[NHPCO's Side-by-Side Comparison](#)

### **Information and Resources**

▶ **The Duke Institute on Care at the End-of-life (ICEOL)** announces a trilogy of plays on end-of-life that inspire conversations as they educate. The plays were written for a general audience and are meant to be used by congregations, hospices, divinity schools, medical schools, and other organizations to raise awareness and initiate conversations around end-of-life care.

Director Richard Payne states that, *‘The three works, in markedly different contexts, spark non-threatening conversation about issues of vital concern. Each of the plays provides a rich opportunity for self-examination and community dialogue on fundamental questions surrounding death and dying.’*

To learn more about the plays and how you can stage one of these plays in your community, contact [Whitney Yadav](#) by email or call her at 919-660-3553.

► **Essential Practices in Palliative Care:** [The International Association of Hospice & Palliative Care \(IAHPC\)](#) has announced an opportunity for Hospice and Palliative Care health care professionals to participate in a project which will benefit the provision of care for patients with life-threatening conditions on a global level. The IAHPC is working towards the identification and development of a list of essential practices in palliative care, and they are looking for physicians, nurses, health clinicians, and health aides from all over the world to participate in a Delphi process.

If you are:

- ✓ 18 years or older
- ✓ Either a physician, nurse, nurse aide, health clinician involved in palliative care delivery, either daily or occasionally
- ✓ Have access to the internet
- ✓ Understand medical terms in English
- ✓ Interested in participating in this study

Then send an email to IAHPC [admin@iahpc.com](mailto:admin@iahpc.com) before **January 31st, 2010**.

► **Advanced Care Planning Booklets Revised:** Excellus Blue Cross and Blue Shield along with the NYS Bar Association partnered to work on the 'Community-wide End-of-life & Palliative Care Initiative' to update their [Advanced Care Planning Booklet](#) to include the 'Five Easy Steps' of the CCCC and MOLST program, in both English and Spanish. It is now co-branded and available on the [Compassion and Support](#) site; you can download the booklet using the link above.

► **The Center for Medicare and Medicaid Services (CMS)** regularly posts answers to payment policy and coverage questions on the CMS Hospice Center. If you or your hospice have questions, follow the link below where you will find a forum with previously and frequently asked questions and answers in the section of the website entitled, "[How to Stay Informed – Questions and Answers: Hospice.](#)"

## **Professional Development and Education**

► **Book Review: TALKING ABOUT DEATH** by Virginia Morris addresses the cultural, personal, medical, and legal concerns that are necessary for us--as individuals and as a society--to prepare for a good death. A good death is described as a death where the dying are in control and not, as is too often the case, caught in a downward spiral of medical intervention and misunderstood intentions. Author Virginia Morris skillfully weaves together personal stories and practical matters, scientific fact and spiritual sensitivity into an important book about how we can achieve a greater sense of peace in dying, and rediscover the art of living. To read reviews and preview several chapters of the book, follow this [link](#).

► **The American Journal on Intellectual and Developmental Disabilities** recently published the results of a research survey entitled, '*Proxy Healthcare Decision Making for Persons with Intellectual Disability*', that was designed to assess the relative influence of several information sources and decision factors when non-family member healthcare proxies engage in decision making for persons with a developmental or intellectual disability. The research population targeted was residential agency directors in Pennsylvania, chosen because the population health characteristics in Pennsylvania are generally similar to those of other US states.

The authors conclude that, '*More research is needed to understand the process of proxy decision making in order to determine what constitutes the 'best interests' of these*

*vulnerable individuals and to better develop guidelines that would improve the quality and consistency of the healthcare given to them.*' The survey results also determined that the most important decision factors were physician recommendations and input from the actual person about their wishes, if possible. Less important were family input and wishes, residential care staff recommendations, and their medical records and health status. The factors with the least influence were accorded to religious affiliation and extra cost to agency.

For those who do not have access to the November 2009 issue of the journal and would like to read the article in its entirety please contact me at [kconnell@hpcanys.org](mailto:kconnell@hpcanys.org) and I will supply you with a hard copy.

► In November, 2009 the **Journal of Palliative Medicine** published a very informative, very useful one page information sheet written by Hospice Chaplain Frank Clore, which provides the reader with a few simple questions (below) that can assist the professional in determining if a patient has decision-making capacity. Clore states that any qualified medical caregiver can assess capacity and make health care decisions with these types of questions and that a determination is not a one-time event, but rather it should be assessed in relationship to a specific decision, at a specific time and in a specific context as a person's capacity may 'wax and wan' even with a diagnosis of dementia.

1. *Please tell me what you understand about your illness and what is being proposed to help you?* This tests the ability to understand and appreciate the decision.
2. *What do you think about this plan? Why? How will this help you? What might happen if this is not done?* These questions clarify that the individual has thought about the pros and cons of the plan.
3. *To help me understand what you said, will you tell me again what your decision/choice is?* Regardless of the method of communication, this clarifies that the individual is able to communicate their decision and that their decision is consistent.

Again, for those who do not have access to the November 2009 issue of the journal and would like to read the article in its entirety please contact me at [kconnell@hpcanys.org](mailto:kconnell@hpcanys.org) and I will supply you with a hard copy.

► **The Advocate Institute is offering their Deluxe Webinar Collection CD: 32 Ways to Become a Better Advocate.** The CD contains 32 of the 90-minute Advocate Academy Webinars conducted between the Fall of 2006 and the Spring of 2009 plus all related materials. This offers you or your organization over 48 hours of information presented by the nation's leading experts on an array of topics critical to special education advocacy. You can view all webinar titles by following this [link](#). If interested use the following link to purchase the collection for only \$49. [Advocate Academy Deluxe Webinar Collection CD](#)

► **Center to Advance Palliative Care (CAPC)** announces an important upcoming Audio Conference:

[Incorporating Palliative Care Services into Long Term Care Facilities](#)  
Thursday, March 25<sup>th</sup> 2010 from 1:30pm – 2:30 (Eastern Standard Time)

This presentation will discuss several models for increasing access to palliative care within long term care settings and speaks to some of the barriers that currently exist and will address the following objectives:

- Describe the demographic imperative and need for palliative care in long term care settings;
- Discuss current models of practice;
- How hospital palliative care programs impact hospital mortality data; and

- Discuss bedside care expectations for palliative care in long term care settings.
- \*\* If you would like to register for this conference, take a look at the other educational opportunities currently being offered, or learn about the Continuing Education Credits available, simply follow this link: [CAPC Audio Conferences](#)

**Announcement**  
**Proposals are now being accepted for the 2010  
 Developmental Disabilities Hospice and Palliative Care Forum  
 Topics!**

**The Developmental Disability Hospice & Palliative Care Forum** is moving to a new platform and will resume again in the Spring of 2010. We are happy to announce that we are accepting proposals from professionals in the community who would like to host a forum discussion.



**If you are interested in:**

- ✓ Educating forum members on cutting-edge topics and ideas related to end-of-life care
- ✓ Highlighting your programs on a statewide platform
- ✓ Presenting important research outcomes
- ✓ Networking with over 350 end-of-life health care professionals
- ✓ Gaining recognition in the hospice and palliative care field

Then please follow this link to [complete the RFP](#) and submit to HPCANYS, or email me at [kconnell@hpcanys.org](mailto:kconnell@hpcanys.org)

**Upcoming Events ~~ Mark your Calendar**

<p><b>Webinar</b>  <b>Wednesday, February 3rd</b>  <b>2:00pm</b></p>	<p style="text-align: center;"><b>‘Supporting Parents When a Child Has a Disability Webinar’</b>  <i>is offered by the NYS Parenting Education Partnership</i></p> <p>Moderator: Wendy Bender, LCSW, - Prevent Child Abuse New York, Healthy Families New York Training and Staff Development Specialist.</p> <p>Parenting a child with a disability can evoke many strong emotions. Most parents experience a process of grief as they learn to adjust and define new expectations. Understanding these emotions and how they influence thoughts and behaviors can be very challenging. This can be very helpful for providers who are working to support parents and for parents working through the process themselves.</p> <p><b>Participants will:</b></p> <ul style="list-style-type: none"> <li>✓ Learn about and understand the stages of grief, with practical, real-life examples.</li> <li>✓ Appreciate the importance of emotional experiences in the process of healing and the risks of avoidance.</li> <li>✓ Be able to define, “What is my role and how can I best support a parent?” or “How can I understand what I am going through and be supportive of myself?”</li> </ul> <p><b>Reserve your Webinar seat now at:</b>  <a href="https://student.gototraining.com/18w5z/register/2236476515442807032">https://student.gototraining.com/18w5z/register/2236476515442807032</a></p>
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<p><b>Thursday, Feb 4<sup>th</sup> 2010</b> Gotham Hall, NYC</p>	<p align="center"><b>National Down Syndrome Society (NDSS) Gala &amp; Auction</b></p> <p><b>NDSS</b> invites you to join more than 300 supporters at Gotham Hall in New York City to celebrate the NDSS mission, the accomplishments of individuals with Down syndrome and those who contribute to the Down syndrome community.</p> <p><b>Chris Wragge</b>, Co-Ancor, CBS Saturday Early Show will once again serve as the Master of Ceremonies.</p> <p><i>For more details and to purchase tickets, visit <a href="#">NDSS 2010 Gala &amp; Auction</a></i>  <i>To download the e-invite from their website, <a href="#">click here.</a></i>  <i>For more information, contact (212) 763-4365 or email <a href="mailto:gala@ndss.org">gala@ndss.org</a>.</i></p>
<p><b>Live Teleconference</b> <i>broadcast via-webcast and satellite on Wednesday,</i> <b>March 21<sup>st</sup>, 2010</b></p>	<p align="center"><b>Hospice Foundation of America (HFA) Announces the</b> <b>2010 National Bereavement Teleconference - Living with Grief: Cancer and End-of Life Care</b></p> <p>The teleconference will address care options related to cancer diagnoses as well as loss and grief reactions for patients, families and professional caregivers and will examine psychosocial aspects of cancer, pain management, and ethical issues related to the disease.</p> <p align="center">To participate: <a href="#">Register online now</a> or <a href="#">mail/fax your registration form.</a></p>
<p><b>April 16<sup>th</sup>, 2010</b></p>	<p align="center"><b>2<sup>nd</sup> Annual National Health Care Decisions Day (NHDD)</b></p> <p>The <b>(NHDD)</b> initiative is a collaborative effort of national, state and community organizations committed to ensuring that all adults with decision-making capacity in the United States have the information and opportunity to communicate and document their healthcare decisions.</p> <p>If you or your organization is interested in learning more, or to download the application or participation form please visit: <a href="http://www.nationalhealthcaredecisionsday.org/">http://www.nationalhealthcaredecisionsday.org/</a>.</p>
<p><b>April 22 - 24, 2010</b> Omni Shoreham Hotel Washington, DC</p>	<p align="center"><b>NHPCO's 25th Management and Leadership Conference:</b> <b>'Securing Our Roots, Expanding Our Reach'</b></p> <p>Each year NHPCO designs new educational programming for the Management and Leadership conference, reflecting the latest trends and innovations in hospice and palliative care and addressing all aspects of management and leadership. NHPCO invites leaders in end-of-life care to attend this conference.</p> <p align="center">To learn more or to register use the following link: <a href="http://www.nhpco.org/i4a/pages/index.cfm?pageID=5998">http://www.nhpco.org/i4a/pages/index.cfm?pageID=5998</a></p>
<p><b>May 13<sup>th</sup> &amp; 14<sup>th</sup>, 2010</b> Marriot Hotel 189 Wolf Road, Albany, NY</p>	<p align="center"><b>HPCANYS 30th Annual Interdisciplinary Seminar and Conference</b> <b><i>Mission – Vision – Reality ... Celebrating 30 Years!</i></b></p> <p>This annual event promises to be as amazing and deeply thought provoking as in years past. It is designed to provide opportunities for networking, education, and thoughtful discussion about end-of-life care.</p> <p align="center">This year HPCANYS is celebrating its 30th year of service!!! If you can make it, it's well worth the trip.</p> <p align="center">For more information visit: <a href="http://hpcanys.org/index.asp">http://hpcanys.org/index.asp</a></p>

**May 20 & 21, 2010**  
Holiday Inn  
232 Broadway Saratoga  
Springs, NY

**SAVE THE DATE!**  
**19th Annual Third Age Conference**  
**Sponsored by the New York State Third Age Committee**

The Third Age Committee is dedicated to focusing on issues for aging persons with developmental disabilities, they sponsor this annual conference, provide a network of experienced trainers, as well as guidance and feedback to New York State's Office of Mental Retardation and Developmental Disabilities Aging Services.

More information about this event will follow, but to learn more visit the [Program in Aging and Developmental Disabilities](#) website.

*You are receiving this newsletter because you subscribed through the [Developmental Disabilities and Palliative Care Forum](#). If you no longer wish to receive this newsletter, please click [here](#) to e-mail the newsletter editor.*