



# Developmental Disabilities Hospice & Palliative Care

## E-Newsletter

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Editor: *Kimberly Connell*

### In the News

#### I/DD Hospice and Palliative Care Issues

##### **NY Times Article: [At End-of-Life Denial Comes at a Price](#)**

The NY Times recently reported on an end-of-life study conducted by researchers at the Dana-Farber Cancer Institute in Boston. Researchers asked patients who had about six months left to live, whether they and their doctors had discussed their wishes for end-of-life care. Of those interviewed, researchers estimate conservatively that those patients who spoke with their doctors incurred \$1,876 in medical costs in their final week of life, compared to \$2,917 for those who did not. Why such a big difference? Dr. Holly Prigerson, a professor of psychiatry at Harvard Medical School and an author of the study, explained that the patients who never talked about their end-of-life wishes were more likely to be resuscitated, intubated or put in intensive care, or all of the above.

According to this study, not only did the patients who received aggressive treatment not live longer overall, but based on reports from family members and other caregivers, they also suffered more physical distress in the end. Patients who had had those end-of-life conversations generally opted for comfort, or palliative, care at home or in a hospice at much lower cost. Dr. Prigerson said, "The study suggests that as costs go up, the misery and suffering index also goes up."

**End of Life Care Costs:** On May 15<sup>th</sup>, the 'Brian Lehrer Show,' a broadcast of NY Public Radio featured an interview with journalist Judy Bachrach and NY Times columnist David Leonhardt regarding end-of-life care costs. David Leonhardt recently interviewed the President about the economy and end-of-life policies and Judy Bachrach has been a supporter of hospice in her blog, [thecheckoutline.org](http://thecheckoutline.org). This is an important and very interesting discussion regarding the difficult choices with end-of-life care and health care reform; rationing of health at end of life; financial incentives for the medical community providing end of life care and the correlation between medical spending and quality of outcomes. We invite you to listen to this conversation by following this [link](#).

Also, if you are interested in reading the NY Times article, click [here](#).

## **Public Policy News**

► President Obama and Congress approved a moratorium on the hospice funding cuts earlier this year, but it expires on September 30, 2009. Without action by the Administration and Congress, hospice reimbursements through Medicare will be reduced by 3.1 percent in fiscal year 2010, leaving hospice programs nationwide, particularly smaller and rural ones, facing cutbacks in services and possible closure.

In a strong advocacy effort, more than 700 hospice providers from across the country visited their Representatives and Senators last month as a part of NHPCO's annual Capitol Hill Day and urged them to protect the hospice benefit. In addition to the meetings in Washington, D.C., thousands of phone calls were made through NHPCO's first Virtual Hill Day. *Were their voices heard?* Well, last week a bipartisan group of **171** Members of the U.S. House of Representatives sent a letter to President Barack Obama showing their support to protect access to high-quality end-of-life care for the 1.4 million patients, and their families, who depend on hospice each year. In the letter, lawmakers urged the President to stop cuts to the Medicare hospice benefit scheduled to begin on October 1, 2009, which threaten to jeopardize the compassionate care the nation's hospices provide to the dying.

This strong showing sends a clear message to the President that he has the bipartisan support from the Houses of Representatives to rescind the CMS Hospice Funding cut permanently.

## **Advocacy Opportunities**

### **► Worldwide Palliative Care Alliance Launched**

It is estimated that more than 100 million people and their families worldwide need palliative care and support each year, however, it is estimated that only seven percent actually receive it. May 5 was the official launch of the Worldwide Palliative Care Alliance (WPCA), a new global action network designed to focus exclusively on hospice and palliative care development worldwide. The WPCA is an alliance of national and regional hospice and palliative care organizations, bringing together people around the world with a shared vision of universal access to quality palliative care. This includes NHPCO and FHSSA. Learn more about [WPCA online](#).

### **► Medicare/Hospice Reimbursement Legislation**

Time is short for the White House to intervene on behalf of hospice on this issue. Without action, hospice reimbursement through Medicare will be reduced by 3.1% on October 1, 2009. As noted above, the president received a clear message from the House of Representatives regarding the preservation of Hospice benefits, but it is now time for *Your Senators to Act to Protect Hospice*. Your voices make a difference, so use this [link](#) to contact your Senator(s) to urge them to respond with as strong and unified voice as did the House of Representatives.

### **► Co-Sponsors Needed for the Community Choice Act**

The Community Choice Act would allow older adults and people with disabilities, who need an institutional level of care, the choice of receiving their services and supports in their own communities rather than in an institution. This bill was reintroduced in March but still

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needs representatives to sign on as co-sponsors for the bill to have a chance of passing. Please Contact your [Congressional representative](#) and urge your legislators to add their support as co-sponsors of this important bill.

## **Information and Resources**

### **► Inside out Documentaries: A Radio Series on End-of-Life Care in America**

This new documentary about end of life care in America investigates what prevents many patients from having a dignified death by asking the question, ‘how can a dignified and respectful death match a medical culture in which death is considered a failure?’ From well-intentioned but maybe unwarranted medical interventions, to the pressure from family members, to the difficult decisions doctors (who are trained to extend survival) have to make when treating elderly or chronically ill patients, this program delves into what challenges exist in America to providing proper end-of- life planning and a "respectful death." The documentary tells human stories as it follows several patients in their last months as they confront some of the most difficult decisions of their lives – whether they should pursue aggressive and sometimes painful medical treatments that may extend survival or focus on how to maintain the best quality of life in their final months. To visit the website or listen to this presentation click on the following link: [Quality of Death: End-of-Life Care in America](#)

### **► Ruby's Bequest – A Unique Collaborative Storytelling Experience**

Experts are predicting that, in the near future, there will be shortages of paid care-givers and direct service providers, shortages in government resources to assist people who use care services, and an influx of people who will need said services as more persons with disabilities start aging, and as more of this population start aging into disability.

**United Cerebral Palsy** (UCP), in collaboration with the Institute for the Future (ITFF) and AARP is sponsoring a unique collaborative storytelling experience called Ruby's Bequest. Ruby's Bequest is a, “massive multi-player future forecasting role-playing experience for people with disabilities and people without disabilities alike.” So essentially it is an online game format story-telling project that aims to provoke a massive brainstorming session among all its participants. During the course of the project, participants will be presented with various future scenarios containing various care-giving related problems. They will then have to put their heads together and imagine creative solutions to those problems. Hopefully it will also serve as the beginning of a conversation about a new, more holistic and sustainable way to look at the role of caring in society.

Ruby's Bequest engages people by introducing them to the fictional town of Deepwell, USA. In the scenario a resident named Ruby Brown has left a large estate to the town on the condition that its citizens improve how they care about their own people. In order to do this the citizens of Deepwell are asking for advice from people all over the world about how to better care for the town's citizens.

If you would like to participate in this project or simply read what other participants have devised to solve the issues presented follow this link: [Ruby's Bequest](#)

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► **OMRDD has Launched (2) New Online Resources:** Simply follow the links below to view these new pages and take advantage of the resources provided there.

### [Aging Information Corner](#)

By 2025 the average person served by OMRDD will be 50 years of age. This is an increase from almost 30 percent in 2003 to more than 33 percent in 2007. Part and parcel of OMRDD's mission is to address the primary issues connected with providing this growing population with an optimum quality of life. This web page is designed as a resource for individuals, their families, advocates and providers to access information and resources on aging with a developmental disability. If you visit this site you may want to take the time to complete the online survey designed to help OMRDD with their mission to help individuals with Developmental disabilities (and their families) live richer lives.

### [Autism Information Page](#)

OMRDD has added a new page dedicated to autism information to its website. As the State service agencies grapple with how to respond with supports and services that meet the needs of this increasing population, the need to communicate what we're doing, our progress in achieving what we set out for ourselves, and to provide valuable information to people living with autism, have become very clear. This new Web page detailing our many initiatives, including our comprehensive Autism Platform announced in May 2008, is one significant step toward bringing this important information to our public.

► The Hospice Foundation of America (HFA) presents an interview with Claire Lavin on the topic of Grief and Loss Challenges for those with Developmental Disabilities. Claire is a professor of psychology at the College of New Rochelle in Westchester County, New York. She also works with children and adults with disabilities in facilities and school as well as a licensed clinical and school psychologist. The HFA has recently published a chapter titled "Persons with Intellectual Disabilities: Facing Dying and Loss" which appears in HFA's upcoming 2009 teleconference companion book, Diversity and End-of-Life Care. Click [here](#) to view the table of contents, follow the link below to read the interview.

### [Grief and Loss Challenges for those with Developmental Disabilities](#)

## ***Professional Development and Education***

### ► **Book review:** [Mastering Communication with Seriously Ill Patients](#)

Physicians who care for patients with life-threatening illnesses face daunting communication challenges. Patients and family members can react to difficult news with sadness, distress, anger, or denial. This book defines the specific communication tasks involved in talking with patients with life-threatening illnesses and their families. The book offers both a theoretical framework and practical conversational tools that the practicing physician and clinician can use to improve communication skills, increase satisfaction, and protect themselves from burnout.

Topics include delivering bad news, transition to palliative care, discussing goals of advance-care planning and do-not-resuscitate orders, existential and spiritual issues, family

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conferences, medical futility, and other conflicts at the end of life. Authors Dr. Anthony Back, Dr. Robert Arnold, and Dr. James Tulsy bring together empirical research as well as their own experience to provide a roadmap through difficult conversations about life-threatening issues. To learn a little more about the book as well as how to purchase it, follow this [link](#).

► **Center to Advance Palliative Care (CAPC) Campus Online:** CAPC offers a continual electronic-learning space for any physicians, nurses, social workers, hospital administrators, chaplains and others interested in starting or expanding a palliative care program. On this campus you'll find courses covering all the structural, operational and financial essentials of palliative care program development and sustainability. The palliative care e-learning courses offer you or members of your team complete flexibility because they are available 24 hours a day, seven days a week. Logon and take the courses whenever you are available! CAPC is also announcing that their courses are now offered at the cost of **\$35** per course, per student. If you would like to learn more about CAPC, take a look at the courses currently being offered, or learn about the Continuing Education Credits available, simply logon to:

[CAPC Campus Online](#)

### **Developmental Disabilities Hospice & Palliative Care Online Discussion Forum**

Is a great source of information for those who are interested in creating supportive teams around individuals with developmental disabilities who are at the end of life?



~~The goal of the forum is to improve end of life care for persons with developmental disabilities through greater utilization of hospice and palliative care services.

~~The forum was developed to provide a safe and accessible platform that would encourage a learning dialog to take place between the developmental disabilities and the hospice/palliative care service provider communities and advocates.

~~ The forum features a professionally facilitated discussion board where registered members are able to post questions and concerns and then receive answers from experts and/or their peers on a specific topic.

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Each of you have a wealth of experience and knowledge to share, together we can create a thriving community where knowledge, ideas and experiences are shared to improve end of life care for persons with developmental disabilities and all who are close to them.

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### **Please join us for our June discussion: Anxiety / Agitation /Delirium Symptom Management**

Want to join in the discussion? Not yet a member?

**Joining is easy!** Simply visit the forum's registration page [Here](#) and register today!

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## Upcoming Events ~~ Mark your Calendar

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| <p><b>May 28-29, 2009</b></p> <p>Saratoga Hilton<br/>534 Broadway<br/>Saratoga Springs, NY</p>                                                                                                                                                  | <p style="text-align: center;"><b>HPCANYS' 29th Annual Interdisciplinary Meeting and Seminar<br/>"Embracing Change...Transforming the Future"</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.<br/>If you can make it, it's well worth the trip.</p> <p style="text-align: center;"><b>Kristen M. Brennan, MT-BC</b>, a Board Certified Music Therapist from the Elizabeth Seton Pediatric Center in NYC has been chosen to receive a free registration to HPCANYS 29th Annual Interdisciplinary Meeting and Conference.<br/>Congratulations Kristen and thank you for your participation on the DD Hospice and Palliative Care Forum!</p>        |
| <p><b>June 15<sup>th</sup>, 2009<br/>6-8pm</b></p> <p>O.D. Heck Development<br/>Center – Bldg 5<br/>Balltown Rd, Schenectady,<br/>NY</p>                                                                                                        | <p style="text-align: center;"><b>Fathers Network Meeting</b></p> <p>The Fathers Network was developed to support fathers who are facing the emotions and challenges of parenting a child with special needs. All dads are invited to join the group and network with other fathers who have 'been there'.</p> <ul style="list-style-type: none"> <li>◆ Share stories of success</li> <li>◆ Share concerns or frustrations</li> <li>◆ Engage in valuable conversations</li> <li>◆ Open to dads, uncles, male siblings, grandfathers, step fathers</li> <li>◆ Join us for coffee, soda, snacks</li> </ul> <p style="text-align: center;">To RSVP for this event or for more information please contact Jim Swart at:<br/><b>(518) 381-4350 ext. 26</b> or <a href="mailto:jmswart1@verizon.net">jmswart1@verizon.net</a></p> |
| <p>Main Conference Dates:<br/><b>September 24<sup>th</sup> -26<sup>th</sup>,<br/>2009</b></p> <p>Preconference Seminar<br/>Dates:<br/><b>September 22<sup>nd</sup> - -23<sup>rd</sup><br/>2009</b></p> <p>Hyatt Regency<br/>Denver Colorado</p> | <p><b>NHPCO's 10th Clinical Team Conference Facility Based Hospice Forum Scientific Symposium Pediatric Intensive Soaring to New Heights in Interdisciplinary Care.</b></p> <p>The 10th Clinical Team Conference and related educational offerings will provide an opportunity for hospice and palliative care providers and professionals to learn about programs and professionals who are "soaring to new heights" in exceptional care, innovative service, increased access, community engagement, quality assessment, performance improvement, interdisciplinary team function and related areas of excellence.</p> <p style="text-align: center;">For more information, visit the <a href="#">conference website</a></p> <p style="text-align: center;">See the <a href="#">Agenda</a> at a glance</p>                |

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**Tuesday June, 23<sup>rd</sup> 2009**

## **MOLST Conference**

Heritage Restaurant at Indian  
Hills Golf Course  
1959 Indian Hills Road  
Painted Post, NY

The **MOLST Conference** is an all-day educational program responding to the recently approved MOLST legislation in New York State. Patricia Bomba, M.D., a national expert, will lead the conference in patient and system-based approaches to implementation of the MOLST Program for seriously ill adults.

The conference will address:

- The importance of effective communication
- Documentation of medical orders on a standardized form
- Ensuring health care providers are trained to honor patient preferences

The deadline for registration is June 8, 2009. Registration fee of \$35.00.

Seating is limited!

Please call Marie at 607 962-6162 for more information.

***As Always - We want to hear from you!***

**We welcome suggestions on content for our monthly newsletter!**

Would you like us to list your event?

Do you have a story to tell?

Do you have a best practice to share?

If any of our readers come across any news, advocacy opportunities or policy issues they would like to share, or if you have a specific topic that you would like addressed in the newsletter or in a forum discussion, click [here](#) to send it along to Kimberly Connell, the newsletter editor.

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