



Developmental Disabilities Hospice & Palliative Care

E-Newsletter

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**National Hospice/Palliative Care Month and World Hospice & Palliative Care Day
Are Fast Approaching!**

**November is Hospice/Palliative Care Month!
October, 11th is World Hospice and Palliative Care Day!**

This is the time of year that Hospice and Palliative Care achieve a national spotlight. These are two unifying events that represent great opportunities to increase awareness of hospice and palliative care for everyone. For a great collection of ideas and materials and ideas on ways to promote awareness, please visit the National Hospice and Palliative Care Organizations website: [NHPCO](http://NHPCO.org)

In the News

I/DD Hospice and Palliative Care Issues

► The New York Times reported that last week Congress passed a bill expanding protections for people with disabilities and overturning several recent Supreme Court decisions. The bill expands the definition of disability, to assure that protection cannot be denied because an individual's disability could be controlled by medications or other measures. *To learn more click below.*

[Congress Passes Bill to Expand the Definition of Disability](#)

► A study published in the Sept. 8 issue of *Archives of Internal Medicine* reports that introducing Palliative Care leads to cost savings. Treatment for seriously ill patients cost dramatically less when palliative-care teams in hospitals were brought in early and matched their therapeutic strategies with goals set by patients. Palliative care teams interview patients and their families early in treatment to identify what they want from therapy and day-to-day care. *To learn more click below.*

[Palliative Care Programs Lead to Cost Savings](#)

► The Social Science & Medicine journal recently published the findings of an end of life research study that was conducted by Duke University in 2007. The article reports that, not only does hospice save the Medicare program around \$2300 for each person who dies while using Hospice, but increasing the length of hospice use by just three days would increase savings by nearly 10 percent, from around \$2,300 to \$2,500 per hospice user.

Lead author, Don H. Taylor, Jr., writes, *“Given that hospice has been widely demonstrated to improve quality of life of patients and families...the Medicare program appears to have a rare situation whereby something that improves quality of life also appears to reduce costs.”*

The outcomes of this study contain powerful messages that hospices can use for outreach to referral sources, community partners and consumers.

To read the entire article, please use the following link:

[*What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program?*](#)

► On August 1st, Reuters reported that The Centers for Medicaid and Medicare Services (CMS) announced that, effective October 1st, 2008 it will be cutting Medicare reimbursement rates for hospice. If passed, the average hospice reimbursement would be reduced from current levels by more than 4.5% over three years. This is a cut that may force many hospice providers across the country to either significantly scale back the care they provide to terminally ill patients or to shut their doors altogether.

To read the entire story, click below.

[*Administration Move Jeopardizes Hospice Care*](#)

► On September 11th, 2008 the Medicare Hospice Protection Act, (H.R. 6873/S. 3484) was referred to the House Committee on Ways and Means. The Medicare Hospice Protection Act would delay implementation of the phase out of the Medicare hospice budget adjustment proposed by the CMS throughout the fiscal year 2009.

To learn more, click below.

[*Lawmakers Introduce Bill to Put Hold on Cut to Hospice Medicare Reimbursement*](#)

Public Policy & Advocacy Opportunities

~ Advocacy efforts are growing to prevent Hospice rate cuts ~

A Call to Action

NHPCO and the Alliance for Care at the End of Life are calling for all hospice supporters to contact their legislators to encourage them to support [*The Medicare Hospice Protection Act*](#).



Simply follow this link to the [Legislative Alert Center](#) ~ from this site you can send a letter to your elected officials to support the [Medicare Hospice Protection Act](#). Read the following article to see what effect the public response has already had on this issue!

[Public Support for Stopping Hospice Rate Cuts Grows](#)

If passed, the [Inclusive Home Design Act](#) would establish standards of "visitability" in all newly constructed, federally assisted, single-family houses and town houses. This means that all new constructions would be required to include at least one floor that complies with accessibility features for persons with disabilities. The bill is currently in the Subcommittee on Housing and Community Opportunity and has only 23 congressional co-sponsors to date.



Just follow this link to learn more about this bill – or to take action by contacting your Congressional Representative(s) and ask them to sponsor this bill that would create more accessible housing for people with disabilities!

~~ Next month we will feature information regarding the 2008 presidential candidate's views on issues concerning persons with intellectual and/or developmental disabilities as well as end of life care issues ~~

Information and Resources

Journal of Religion, Disability and Health Hawthorn Press is offering a free sample of this publication. The journal focuses on research, policies, and practices that unite religious personnel with health care professionals and researchers to develop more holistic supports and inclusive communities for people with disabilities. The Journal of Religion, Disability & Health also supplies an equal place 'at the table' for the voices of people with disabilities and their families as they encounter and address services and supports in the world of faith and health. Use the following link to access the journal.

[Journal of Religion, Disability and Health](#)

EndLink: A Resource for End of Life Care

This site provides educational modules that can be viewed or downloaded in PDF form. You will find information on advance directives, communication of bad news, whole person assessment and goals of care, management of pain and other symptoms, the last hours of living, assisted suicide debate, legal and financial issues, as well as cultural, social, psychological, and spiritual concerns in end of life care. The palliative care concepts expressed in this educational material are applicable across the entire spectrum of health care, not just in end-of-life care.

Click [Here](#) to access the information and materials on this site.

Developmental Disabilities Hospice & Palliative Care Discussion Forum

This online discussion forum is a collaborative initiative by NYSARC Inc. and The Hospice and Palliative Care Association of New York State, with funding provided by the NYS Developmental Disabilities Planning Council.

~~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 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 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. If you have not yet signed up for the forum, please do so today! Each of you have a wealth of experience to share, and together this can be a thriving community with shared ideas to improve end of life care for persons with developmental disabilities and all who are close to them.

Joining is easy! Simply visit the forum's registration page at, <http://www.ddhospicepalliativecare.org/register.cfm> and register today!

Upcoming Events ~ Mark your Calendar

Oct. 30 - Nov. 1, 2008 Albany Marriot Hotel 189 Wolf Road, Albany, NY	18th Annual Self-Advocacy Association of NYS Statewide Conference This annual conference brings together people with developmental disabilities, their families and caregivers and offers a variety of workshops and focus groups to learn together and share their experiences with self-advocacy. For information and registration call: (518) 458-8444 **Scholarship funds are available for support staff**
November 24th, 2008 Desmond Hotel and Conference Center in Albany, NY	12th Annual Alzheimer's Association Conference for Caregivers This annual conference is a wonderful opportunity to hear from leaders in the field of Alzheimer's disease and learn about the latest in research and treatment options. At the conference you can attend a variety of workshops, experience the Virtual Dementia Tour, and visit with the more than 30 exhibitors who will be there to showcase their products and answer your questions. For more information: Call Gretchen at: 438-2217 ext 208 Email: gretchen.moore-simmons@alz.org
May 28-29, 2009 Saratoga Hilton 534 Broadway Saratoga Springs, NY	HPCANY'S' 29th Annual Interdisciplinary Meeting and Seminar "Embracing Change...Transforming the Future" 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. <i>If you can make it, it's well worth the trip.</i> HPCANY is providing one free registration to this conference! This opportunity is only for those forum members who have posted on at least one discussion board. The lucky recipient will be chosen in a random drawing raffle

Newsletter Contributions Welcome!

We welcome suggestions on content for our monthly newsletter! Do you have a story to tell? A best practice to share? If any of our alert 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 the newsletter editor.

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