



## E-Newsletter

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### News

#### **Palliative Care Act Passes in New York**

First, great news for New Yorkers! The **Palliative Care Education and Training Act** has passed this legislative session. This wonderful program, which was vetoed last year, will receive nearly \$4.6 million in the 2007-2008 New York state fiscal budget. The bill, commonly referred to as the Palliative Care Act, was designed to improve palliative care and pain management through educational initiatives establishing palliative care training programs for students in medical fields, identifying and funding several Centers for Palliative Care Excellence, and creating a New York State Palliative Care Education and Training Council to guide state policies on pain management and other aspects of palliative care. For more information, visit <http://www.nysl.nysed.gov/ils/topics/laws.htm>

#### **Hospice and Palliative Care in the News**

Several interesting articles on hospice care have been published in large national newspapers over the past few months.

On February 10, 2007, *The New York Times* published "A Chance to Pick Hospice and Still Hope to Live." It's an illustrative example of "open access hospice", in which some insurers and health care providers are breaking down barriers to people receiving hospice while still undergoing extensive medical treatments for their life threatening conditions. To view this article, please visit:

<http://www.nytimes.com/2007/02/10/business/10hospice.html?ex=1184731200&en=739fd1badc76315a&ei=5070>

More recently, a July 16, 2007 article from the *Washington Post* addressed disparities in minorities use of hospice services. Using the story of a 97-year-old African American woman with a life-threatening illness as an example, the phenomenon of reluctance of people of non-white ethnicity to use hospice services is discussed and ways that these groups are being reached out to are illustrated. To read this article, visit: <http://www.washingtonpost.com/wp-dyn/content/article/2007/07/15/AR2007071500435.html?referrer=emailarticle>

## ***Information and Resources***

### **Developmental Disabilities Hospice & Palliative Care Forum Now Open!**

This 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 and is a response to a series of training workshops on palliative care. These workshops which took place across New York State brought together developmental disabilities, hospice and palliative care service providers and advocates to collaborate and learn more about innovative ways to improve end of life and supportive care for persons with developmental disabilities, their families, and their paid caregivers. Staff, families and advocates who participated in these workshops formed local and regional collaboratives aimed at sustaining improvement in end of life and supportive care. This forum was created to offer an on-line opportunity for these groups to continue to pursue service and care improvements. Come join the forum and use this as a platform to share ideas, challenges, and questions. Joining is easy. Simply visit the forum's registration page at <http://www.ddhospicepalliativecare.org/register.cfm> and register today! We anticipate beginning discussions by mid-August when the first wave of people have registered.

Many of you may have visited the forum when it was first opened to the public. Due to the vast amounts of spam that quickly found the forum, we have changed the mechanism for registration and posting to the forum so that it is now fully moderated. The forum is now fully operational and carefully guarded against spammers and other offensive content.

### **Last Passages Website Updates**

The [Last Passages](#) website has been updated with lots of new and updated materials! Last Passages is a joint project of the Volunteers of America, the University at Albany, NYSARC, Inc. and Marist College. The purpose of the Last Passages project is to share information and promising practices to enhance end-of-life care for persons with developmental disabilities. If you have not yet visited the site, please check it out at <http://www.albany.edu/aging/lastpassages/index.html>

### **Next Steps for the *Making the Connection* End of Life Care Curriculum**

The **Making the Connection End of Life Care for Persons with Developmental Disabilities Training Monograph** will soon be available on the [Last Passages](#) web site! Some of our readers have attended this comprehensive training geared toward promoting understanding, familiarity and collaborative working relationships between hospice and developmental disabilities staff about the complementary roles each group can play in improving end-of-life care for persons with developmental disabilities. This series of trainings held across New York State represented a collaborative initiative between the Hospice and Palliative Care Association of New York State and NYSARC, Inc. The upcoming monograph summarizes the important aspects of the trainings, as well as best practices and suggestions that arose from the interactive discussions during trainings. We will also post this important document to the [forum](#) as soon as it is available and invite discussion on how facets from this important training might be implemented at the individual and agency levels.

## **Free Hospice and Palliative Care Educational Materials for Professionals**

The National Cancer Institute is offering a new self study CD-Rom, *The Education in Palliative and End of Life Care for Oncology*, for clinicians caring for persons with cancer. If interested, visit <http://www.cancer.gov/aboutnci/epeco> for more information. As people with developmental disabilities age, cancer diagnoses are becoming increasingly prevalent. Though this CD is not geared specifically for care of individuals with developmental disabilities, much useful information can be found in the trainings.

The National Association of Social Workers (NASW) offers a free web-based training, entitled *Understanding End of Life Care: The Social Worker's Role*, a 2 hour self-paced course on end of life care from a social work perspective. Free registration is required to access the course. Other web-based courses are available on cancer caregiving and aging. For more information, visit <http://www.naswweb.org/>

## **Social Work Hospice and Palliative Care Network**

A new organization has been formed for social workers involved in hospice and palliative care to serve both professionals and the public. For further information, please visit <http://www.swhpn.org/>

## **Center to Advance Palliative Care Launches New Website**

CAPC has launched a new website to provide people nearing the end of their lives, their families, doctors, as well as policy-makers with easy-to-understand palliative care information. A key message of the web site is to make it clear to all viewers that palliative care is appropriate and helpful at any stage of illness and is complementary with conventional medical care. The web site is located at [www.getpalliativecare.org](http://www.getpalliativecare.org)

## **Trustee article, Care with Compassion**

*Trustee* is a journal for hospital providers. This particular article presents a candid and fair portrayal of the rewards and challenges of providing palliative care in hospitals, including concrete ways that hospitals can move toward providing palliative care.

[http://www.trusteemag.com/trusteemag\\_app/jsp/articledisplay.jsp?dcrpath=TRUSTEEMAG/Article/data/05MAY2007/0705TRU\\_FEA\\_Care&domain=TRUSTEEMAG](http://www.trusteemag.com/trusteemag_app/jsp/articledisplay.jsp?dcrpath=TRUSTEEMAG/Article/data/05MAY2007/0705TRU_FEA_Care&domain=TRUSTEEMAG)

## **Clinical Practice Guidelines for End-of-Life Communication Issued in Australia**

The Australian government has released new clinical practice guidelines for communicating about end-of-life issues with patients and their families. Though these are based upon Australian culture and health care system, they are well worth a read! To view the guidelines, please visit The Medical Journal of Australia web site at

[http://www.mja.com.au/public/issues/186\\_12\\_180607/cla11246\\_fm.html](http://www.mja.com.au/public/issues/186_12_180607/cla11246_fm.html) Please note that this information will only be available free of charge for a short time.

## **Upcoming Events**

- ***RRTI's Geriatrics and Developmental Disabilities Nurse Training Program.***  
Trainings will include many aspects of aging among people with developmental disabilities, including end of life issues. Sessions are held all across New York to improve access for nurses who wish to participate. Past participants have found this training invaluable in their day-to-day practice with older adults with developmental

disabilities. An informational [brochure](#) is available for download. Register today at [www.rrti.org](http://www.rrti.org) ; seats are still available.

- ***Rochester Series 2007 Aging and Developmental Disabilities: What do We Know?*** This innovative 2-day conference discusses the current state of knowledge on aging and what aspects of this knowledge base can be applied to individuals with developmental disabilities. The conference is being held in Rochester. The first session was July 23<sup>rd</sup>, but the second session will be on August 7<sup>th</sup> from 9am-4pm. Registration is still open for this. For more information, check our forum's [events](#) section!
- ***Building Palliative Care Programs in Hospitals: Tools and Strategies for Success*** is being hosted by The Center to Advance Palliative Care (CAPC) on November 1-3, 2007 in San Francisco, CA. This seminar is designed for people who are seeking to create a palliative care program or who are looking to assess and improve an existing palliative care program. While the emphasis is on hospital-based programs, much information will be transferable to non-hospital settings. For more information, visit <http://www.capc.org> or call 212-201-2680.
- ***AAIDD (Formerly AAMR) Upcoming Regional Conferences***
  - Region IX Conference in Willow Valley Conference Center, Lancaster, PA from September 6-7, 2007 (Registration closes week of August 27<sup>th</sup>)
  - Region X Conference in Portland, ME from October 14-16, 2007
  - For more information about these and other upcoming AAIDD conferences, please visit <http://www.aaid.org/>
- ***American Academy of Hospice and Palliative Medicine and Hospice and Palliative Nurses Association Joint Annual Assembly***. This annual conference is being held from January 30-February 2, 2008 in Tampa Bay, FL. For more information, please visit <http://www.aahpm.org/>

## **Newsletter Contributions**

We welcome suggestions on content for our monthly newsletter! If you have an item you would like to submit, such as news, resources, or upcoming events, please click [here](#) to e-mail Anna Zendell, newsletter editor.

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. Be sure to put unsubscribe newsletter in the subject line.