



## E-Newsletter

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### News

#### **Dementia Care Recommendations for End of Life Care Released by the Alzheimer's Association**

The Alzheimer's Association has just released a comprehensive set of recommendations on end of life care for persons with dementia. Recommendations involve advance care planning, maximizing person-centered palliative care for people with advanced dementia symptoms, and trainings specific to people with dementia nearing or at the end of their lives. Specific topics covered include communication and decision-making strategies involving people with dementia and their families; assessment and care for behavioral and physical symptoms, including pain; psychosocial-spiritual support; supports for people who choose hospice services; death and bereavement services; and staff training. Many of the recommendations are very applicable to persons with intellectual and/or developmental disabilities. To access, please visit [http://www.alz.org/media\\_11127.asp](http://www.alz.org/media_11127.asp)

#### **National Hospice/Palliative Care Month Fast Approaching!**

November is Hospice/Palliative Care Month! This represents a great opportunity to increase awareness of hospice and palliative care. For materials and ideas on ways to promote awareness, please visit: <http://www.nhpc.org/i4a/pages/index.cfm?pageid=3327>

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

Several interesting articles on hospice care have been published in large national newspapers and academic journals over the past several months.

A July 3<sup>rd</sup> article in the *Washington Post*, entitled A new focus on easing the pain: Palliative care helps the very ill shares real stories of people facing end of life -- either their own or a loved one's -- and the ways the health care system is responding, particularly in the area of pain management. To read this article, please visit:

<http://pqasb.pqarchiver.com/washingtonpost/access/1298572001.html?dids=1298572001:1298572001&FMT=ABS&FMTS=ABS:FT&date=Jul+3%2C+2007&author=Joanne+Kenen&pub=The+Washington+Post&edition=&startpage=F.1&desc=A+New+Focus+on+Easing+the+Pain>

The *New England Journal of Medicine's* July 26, 2007 issue recently discussed several hospice-related topics in its *Perspective* section. Calls for response letters

have gone out from a number of agencies, so more on this topic is likely to come in future issues. For more information, check out [www.nejm.org](http://www.nejm.org). If you cannot access this section, feel free to contact Anna Zendell at [ag0814@albany.edu](mailto:ag0814@albany.edu), and request a hard copy.

## ***Information and Resources***

### **AAIDD Aging and End of Life Issues Forum Materials Now Available On-line**

The American Association on Intellectual and Developmental Disabilities (formerly the AAMR) has placed materials from its Aging and End of Life Issues Special Forum on the AAIDD web site. Information specific to end of life and palliative care is available in power point format on issues such as: policy perspectives in end of life care, consumer directed care, housing, quality of care, and principles of palliative care for persons with I/DD. To access these materials, please visit <http://www.aamr.org/Events/aging.shtml>

### **Developmental Disabilities Hospice & Palliative Care Forum 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/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 targeted discussions on topic areas of interest to the hospice and developmental disabilities provider communities. We will be posting featured topics in the next issue of this newsletter. Likewise, if you have a specific topic that you would like addressed, please let Anna Zendell know ([ag0814@albany.edu](mailto:ag0814@albany.edu)).

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.

## ***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, though they are going fast!

- **Contemplative Caregiving: Wisdom & Compassion at the End of Life.** To be held at the Omega Institute in Rhinebeck, NY, on October 21-26<sup>th</sup>. This is a very spiritually focused training on end of life care geared toward health care and mental health professionals, with a great deal of emphasis on self-awareness and self-care. For more information, please see [www.eomega.org](http://www.eomega.org).
- **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 X Conference in Portland, ME, October 14-16, 2007
  - For more information about this 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 January 30-February 2, 2008 in Tampa Bay, FL. For more information, please visit <http://www.aahpm.org/>
- **National Hospice and Palliative Care Organization (NHPCO) Audio Web Seminars.** The NHPCO has another excellent round of audio web seminars listed on its web site. They can be accessed through [www.nhpc.org/i4a/pages/Index.cfm?pageID=5065](http://www.nhpc.org/i4a/pages/Index.cfm?pageID=5065) Here is just a sampling:
  - *Saying Goodbye and Meaning It: Effective Closure with Clear Boundaries for Hospice Workers (9/20/07)*
  - *Pioneering Practices in Palliative Care (9/25/07)*
  - *Assessing and Promoting Resilience in Work with Patients and Families at the End of Life (10/11/07)*
  - *Palliative Sedation at the End of Life (11/8/07)*
  - *Connecting the Dots: Effective Care Planning, Communication and Collaboration Across Settings (12/13/07)*

## 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.