



Developmental Disabilities Hospice & Palliative Care

E-Newsletter

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News

Hospice, Palliative, and End-of-Life Care Issues in the News

Several interesting articles on hospice and palliative care issues have been published in national newspapers over the past month. Several are listed below!

On April 7, 2008, *The New York Times* published “Researchers Find Huge Variations in End-of-Life Treatment”. In this article, Robert Pear discusses large differences in the costs, amounts, and types of care being provided to Medicare-insured individuals with chronic illnesses at the country’s top rated health care facilities. This study raises the possibility of future government cost savings in care, as well as possible national disparities in terms of approaches to aggressive health care in chronic illnesses with relatively poor long-term prognoses across health facilities and possible regional differences in severity of certain chronic illnesses. Based on the information given in this article, follow up investigation will need to be done. However, it is an interesting article to read. For more investigation, please visit <http://www.nytimes.com/2008/04/07/health/policy/07care.html?scp=1&sq=Researched+find+huge+variations+in+end-of-life+treatment&st=nyt>

On March 25, 2008, *The New York Times* published “Guidelines for Epidemics: Who Gets a Ventilator?” It’s a disturbing report about a potential ethical decision-making dilemma as to who would receive ventilators in the event of a public health disaster or similar scenario in which ventilators become in short supply. New York State has put in place guidelines on ventilator distribution in the event of an epidemic or pandemic. To view the guidelines, please visit www.health.state.ny.us/diseases/communicable/influenza/pandemic/ventilators/ To view the NY Times article, please visit: http://www.nytimes.com/2008/03/25/health/25vent.html?_r=1&scp=1&sq=guidelines+for+epidemics%3A+who+gets+a+ventilator%3F&st=nyt&oref=slogin.

Also on March 25, 2008, *Pulse: The GP’s News Website* published “End-of-life care issues in COPD. Patients with COPS nearing the end of their lives have physical and emotional needs at least as pronounced as those of people with other end-stage illnesses. The article describes the importance of advanced care planning as a way

of preparing for end of life, something that has been drawing increasing attention in the developmental disabilities community. To read more of this brief but very interesting article, please visit

<http://www.pulsetoday.co.uk/story.asp?sectioncode=18&storycode=4118060>.

A March 21, 2008 article from *Scripps News* online addressed differences between end-of-life and palliative care for people with life-threatening illnesses and giving patients and their families' education and choices. This is a very empowering article and a great read! To view please visit <http://www.scrippsnews.com/node/31703>.

Information and Resources

Developmental Disabilities Hospice & Palliative Care Forum Upcoming Events!

The forum is now up and running and we have had several successful on-line guest expert moderated forums! We thank Terry Clarke, RN, for preparing great materials and moderating an excellent session on **Team Building between Hospice and Developmental Disabilities Providers**. Then Dr. Geraldine Abbatiello hosted our forum as guest expert, discussing the very challenging and difficult topic of **When to Make the Decision to Let Go** and seek end-of-life care. Her case study was thought-provoking and brought up some great ideas for future discussion topics as well!

Our next guest expert moderated topic will feature Larry Faulkner, attorney specializing in developmental disabilities issues, who will moderate our discussions on **Legal Issues of Providing Hospice Care to People with Intellectual and other Developmental Disabilities**.

This particular topic has been one of the most often request topic areas, so a lot of people are eagerly awaiting the first day of this discussion!

Following the legal issues discussion, one will tentatively begin that will address the often thorny topic of **Billing Issues and Funding of Hospice Care**. We are still awaiting the guest moderators' preferred start date and will pass that along.

We are roughly 1/3 of the way through our first round of planned guest moderated discussion topics. We would love to hear from you what you would like to see featured! In the near future, we will be providing opportunities for you to share your ideas on future topics. This is **your** forum and we want to provide what *you* want to learn more about!

For those of you new to the newsletter, 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!

Several Resources on Helping Adults Cope with Loss and Grief

Much of our focus on the forum web site and other materials have been on death and dying of individuals with I/DD and helping family and paid carers of these individuals cope with the loss and grief. For every person with an I/DD who passes, he or she has friends who also have I/DD and will also grieve. It's our responsibility to address their needs and their grief as well. Likewise, people with I/DD are not immune to losing loved ones. There are several excellent resources on the web on this topic.

Saying goodbye: Supporting people with developmental disabilities through loss and grief is a comprehensive publication developed through the State of Maine's Office of Learning and Development to address issues of grief and loss, with emphasis on suggestions for interventions. To find out more about obtaining a copy, visit <http://www.drm.stte.ma.us/>

Down Syndrome Scotland has some excellent materials on loss, as well, including downloadable handouts and booklets such as *Coping with Loss* (Marsden, 2005) and *Let's Talk about Death (for people with developmental disabilities)* (Watchman, n.d.). To access these and others, visit <http://www.dsscotland.org.uk>

New Article on Palliative Care for Persons with Alzheimer's Disease

An interesting new article has just been published on ethical considerations of palliative care for persons with severe Alzheimer's based on the need to listen to people living with the disease, preventing and alleviating suffering, and improving quality of life. As the numbers of persons with I/DD diagnosed with dementia grow, we will need to address the unique end-of-life and palliative care needs for this group of individuals and those who care for them. The citation is as follows: Mahon, M. M. & Sorrell, J.M. (2008). Palliative care for people with Alzheimer's disease. *Nursing Philosophy*, 9(2), 110-20. If you would like a copy of the article, one should be available within 2-4 weeks. Just e-mail Azendell@uamail.albanu.edu and request a copy.

Upcoming Events

- ***HPCANY'S Annual Interdisciplinary Seminar & Meeting—Threads in the Fabric: Working Together for Quality Hospice and Palliative Care.*** Trainings will include 29 concurrent workshops and 5 concurrent sessions on important, cutting-edge issues in hospice and palliative care, including but certainly not limited to pain and symptom management in hospice and palliative care, the challenges of underserved populations, and getting the best from interdisciplinary teams. This important conference will be held at the Saratoga Hotel in Saratoga Springs May 15-16, 2008. Don't miss it! For more information and to register, visit www.hpcanys.org.
- ***NYSARC 2008 Aging Symposium***
This annual conference, being held on April 23-24-2008 at the Gideon Putnam

Resort in Saratoga Springs, will address topics in the continuum of aging including end-of-life issues including legal issues, transitional issues, guardianships, in-home supports, the effects of grief and loss, spirituality, funeral planning and ethics in decision making and defining quality of life for persons with developmental disabilities and those who care for them. For more information, please contact NYSARC, Inc. at 518-439-8311 or check their web site at www.nysarc.org.

☐ ***AAIDD (Formerly AAMR) 132nd Annual Meeting – The New Professional: Leadership in Science, Practice, Policy and Advocacy***

The AAIDD Annual Meeting will be held on May 28-30th at the L'Enfant Plaza Hotel in Washington DC. A number of workshops and sessions focus on end-of-life planning and care. The AAIDD conferences are providing more session time for end-of-life issues, so it definitely pays to bookmark their conference web site! For more information about this and other upcoming AAIDD conferences, please visit <http://www.aidd.org/>

☐ ***Seventeenth International Conference on Palliative Care.***

This annual conference is being held September 23-26, 2008 in Montreal, Canada. For more information, please visit <http://www.pal2008.com/index-e.html>

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.

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