

Developmental Disabilities Hospice & Palliative Care

E-Newsletter

July 2008 Vol. 2(7)

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. Some are listed below. Though very little is published in the mainstream news media concerning end-of-life care for persons with developmental disabilities, there is much to be learned from keeping up with the current news and trends!

July 1, 2008: **New Palliative Care Ethical Guidelines Released by the AMA.** The American Medical Association has just released a comprehensive set of guidelines on ethical considerations concerning terminal sedation of persons with intractable pain as a part of end-of-life care. The new ethical guideline prohibits use of sedation treatment by physicians to alleviate emotional distress or as a means to end life. Suggestions for other mechanisms to relieve suffering of patients are provided. To read more, visit www.ama-assn.org.

July 1, 2008: **For Hospice a Higher Authority: Medicare Requires More Accountability.** In a special article in the *Washington Post*, author Alicia Ault describes new rules by Medicare calling on hospice providers to more carefully account for the quality of care provided. These rules will take effect in December. They guarantee hospice patients input into their care and require hospice providers to show improvements in areas found to be below standards. For example, patients who choose palliative care over curative care have the right to participation in treatment and pain management planning, to refuse treatment, and to choose their own doctors. For more information, please visit <http://www.washingtonpost.com/wp-dyn/content/article/2008/06/27/AR2008062703021.html> or www.medicare.gov.

June 11, 2008: **End of Life Patients Need Big Picture.** A *USA Today* article states that patients with advanced cancer are often unaware of life expectancy and effects of chemotherapy on quality of life. This article shares the results from a study published in *JAMA: The Journal of the American Medical Association*, in which Medicare beneficiaries were asked about whether they were fully informed of what to expect from chemotherapy. Study results revealed that up to 37% of patients were either not informed or misunderstood the information that they received on effects of chemotherapy, prognosis, and/or mortality. There is also a comprehensive case study associated with this article that can provide guidance for hospice and other end-of-life care providers. For more information, please visit http://www.usatoday.com/news/health/2008-06-10-end-of-life-cancer_n.htm or <http://jama.ama-assn.org/cgi/content/abstract/299/22/2667?maxtoshow=&HITS=10&hits=10&RESULTFOR MAT=&fulltext=chemotherapy&searchid=1&FIRSTINDEX=0&resourcetype=HWCIT>.

Information and Resources

Developmental Disabilities Hospice & Palliative Care Forum Upcoming Events!



We are over half-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! **We have created a short anonymous on-line survey to gain your feedback** on what you want to see on the DD Hospice and Palliative Care Forum. Please visit http://www.surveymonkey.com/s.aspx?sm=Yuf7Mn9VPUGbnyihOk4nYg_3d_3d to complete this short survey. It should take you approximately 5-10 minutes to do and will greatly assist us in planning the next 6-12 months of forum activities to meet your needs! 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 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!

Making the Connection End of Life Care Curriculum

The **Making the Connection End of Life Care for Persons with Developmental Disabilities Training Monograph** is now out in hard copy and portions will soon be available on the **Last Passages** web site! Some of our readers 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.

Center to Advance Palliative Care Audio-Visual Media Sale

CAPC is having their annual summer sale with up to 50% off on audio-visual materials from past seminars on end-of-life care. If interested, it can be a cost-effective way to add to your palliative care library! To learn more, visit www.capc.org.

Peer-Reviewed Articles on End-of-Life Care

Several articles have come out in the past month on various facets of end-of-life care. Here are a couple of particularly relevant articles. Both have been ordered, so if anyone wants a copy, e-mail the [newsletter editor](#) and once they come in, an electronic copy will be forwarded to you.

Birch, D. & Draper, J. (2008). **A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia.** *Journal of Clinical Nursing*, 17(9), 1144-1163. Here is an interesting article on the challenges to providing effective palliative care for older adults with dementia, along with some strategies to overcome some of these challenges. Written from the British delivery system perspective, there are nonetheless many

strategies that can be quite effective within our own delivery systems and which can be adapted to persons with developmental disabilities and dementia.

Hebert, R.S. et al. (2008). What questions do family caregivers want to discuss with health care providers in order to prepare for the death of a loved on? **An ethnographic study of caregivers of patients at end of life.** *Journal of Palliative Care Medicine*, 11(3), 476-483. This article presents the caregiver perspective on questions family caregivers wish to ask but are often not able to ask or otherwise do not receive answers to.

Reader Contribution

Expertise: Eileen's Story

When Eileen was diagnosed with dementia, we the staff of her group home did not know what we were going to do. How would we deal with the Alzheimer's disease on top of the Downs syndrome? We do not have the expertise, but what is expertise? Webster's Dictionary defines expertise as "the skill or knowledge of an expert". Well, an expert on what? We would like to think of ourselves as experts on developmental disabilities, but certainly not medical matters or of aging. However, wait... was it medical? It sure was extensive personal care--much more than we were used to.

Surely, Eileen would be better off in a nursing home with the professionals. Maybe not; what is their ratio? How much time can they spend with her? What 'expertise' do we need? What are her needs and how do we meet them? We don't know how to lift a person, how can we learn? O.K. the first step is figuring out what we do not know that we need to.

Time went on. As skills were learned, additional staff was added, Hospice was contacted, equipment was received, and new protocols were put in place, we began to feel more confident in our ability to meet Eileen's needs. We were gaining "expertise".

We also loved, knew, and understood Eileen. Webster's dictionary defines love as "strong affection". Therefore, we had love *and* expertise now. This so-called expertise will sure come in handy as our next consumer ages and becomes ill. What I did learn was that affection is as important as expertise in caring for someone; Eileen always knew that as she herself was always filled with love.

On Tuesday May 27, 2008 at 7:00AM Eileen Murphy's spirit went to be with her mothers. In Eileen's obituary listed her housemates as "survivors" and ended with the following passage, "**Eileen's family wishes to express their gratitude to the Spaulding Support Services staff at Lancaster house for their kindness and compassion shown to her during her long illness**". That to me encompasses why we did what we did.

*Denise Morini
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Upcoming Events

- **World Hospice and Palliative Care Day - October 11, 2008.** This is a unified day of action to support hospice services around the world. The theme is **Hospice and Palliative Care: A Human Right.** There is still plenty of time to plan public activities to draw attention to hospice

and palliative care in our communities. For more information, please visit http://www.worlddday.org/about_world_day_2008.asp and follow links of interest to you.

- **17th International Congress on Palliative Care - September 26-28, 2008.** Held in Montreal, this is one of the largest conferences dedicated to palliative care issues. For more information, please visit the conference web site at <http://www.pal2008.com/index-e.html>.

Newsletter Contributions Wanted

Do you have a story to tell? A best practice to share? 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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