

# 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. 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!

April 30, 2008: **Massachusetts Health Initiatives to Include End-of-Life Care.** The MA Health Care Quality and Cost Council released its annual report recently, which included a strengthened focus on adherence to patients' wishes in end-of-life care. To read more, visit [http://www.mass.gov/lhqcc/docs/annual\\_report.pdf](http://www.mass.gov/lhqcc/docs/annual_report.pdf).

April 26, 2008: **False Memories of Living Wills May Complicate End-of-Life Treatment Decisions.** Researchers from University of California at Irvine found in a study that many people could not recall their end-of-life wishes from the time they had written their advance directives, and often held false memories of their end-of-life preferences. Many people's wishes for end-of-life care may evolve or change as they age and deal with new illnesses. In the study, this indeed happened for approximately 1/3 of the sample, indicating that advanced directives and other treatment preferences should be revisited regularly and updated as people's preferences change. For more information, visit <http://www.sciencedaily.com/releases/2008/04/080426083329.htm> or read the original journal article in *Health Psychology*. [Reference: Sharman, S.J.; Garry, M.; Jacobsen, J.A.; Loftus, E.F.; Ditto, P.H. (2008). False memories for end-of-life decisions. *Health Psychology*. 27(2) 291-296.]

April 24, 2008: **Medical Technology Creates Ethical Dilemma.** A Washington Post article discusses ethical dilemmas posed by cutting edge medical technology, such as heart pumps. Heart pumps, which were initially implanted as a temporary measure until transplants could take place, are now being kept in people's bodies for years. They can be painful and cause unpleasant side effects. What then is done when people wish to turn off or remove these technologies, which are life prolonging? The discourse is akin for many to that of feeding tube debates. To read more, please visit [http://www.washingtonpost.com/wp-dyn/content/article/2008/04/23/AR2008042303534\\_pf.html](http://www.washingtonpost.com/wp-dyn/content/article/2008/04/23/AR2008042303534_pf.html)

April 21, 2008: **End-of-Life Care Survey of Upstate New Yorkers: Advanced Care Planning.** Blue Cross-Blue Shield has published a report detailing the outcomes of a large-

scale survey of adults in upstate NY concerning their attitudes toward, knowledge about, and completion of advance directives, in particular health care proxies and living wills. Findings included fairly wide disparities between people's perceived importance of doing advance planning and actual activities of advanced care planning. For more information, please visit <https://www.excellusbcbs.com/wps/wcm/resources/file/eb856805385613f/End%20of%20Life%20survey-EX.pdf>.

April 8, 2008: **National Hospice Study Reveals Gaps in Service.** Science Daily recently released a report on gaps in hospice service availability across the United States. Citing funding as a contributing cause, the national hospice study conducted by the University of Michigan found that communities, though more people than ever are served by hospice in their last months, people with lower average incomes, low educational attainment, and those with heavy concentrations of older adults are less likely to have access to hospice services than other communities. For more information, please visit <http://www.sciencedaily.com/releases/2008/04/080411151014.htm> or [www.washingtonpost.com](http://www.washingtonpost.com)

## ***Information and Resources***

### **Developmental Disabilities Hospice & Palliative Care Forum Upcoming Events!**

Our newest guest expert moderated topic features Kirk Lewis, General Counsel for Schenectady ARC, who will moderate our discussions on **Legal Issues of Providing Hospice Care to People with Intellectual and other Developmental Disabilities.**

This topic is one of the most often requested topic areas, so [join the discussion!](#)

Following the legal issues discussion, one will begin in mid-May that will address the often thorny topic of **Billing Issues and Funding of Hospice Care.**

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 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.

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

Palliative Care Toolkit Brings Care to Terminally Ill in Resource-Limited Settings in the United Kingdom. The Palliative Care Toolkit offers a proactive, holistic approach to increase access to palliative care in communities from a lifespan perspective (childhood to old age). This is meant to be an internationally-applicable tool kit, so check it out! To download your copy, visit <http://www.helpthehospices.org.uk/international/index.asp?submenu=1&thirdmenu=4>. If you have difficulty accessing it, please contact the [newsletter editor](#) and a copy will be e-mailed to you directly.

### **Upcoming Events**

- **YAI/NIPD Network's 29th Annual International Conference -- Visions of Hope and Opportunity in Developmental and Learning Disabilities** will be held in New York City May 5-9, 2008. YAI's conferences are always widely attended and cover a large range of topics, including aging, health issues, future planning, and end-of-life related issues. For more information or to register on-line, please visit [www.yai.org/conference](http://www.yai.org/conference).
- **Threads in the Fabric: Working Together - The 28th Annual Meeting of the Hospice and Palliative Care Association of New York State** will be held in Saratoga Springs on May 15-16, 2008. Each year, the HPCANYS conference offers unique opportunities for networking, education, dissemination of cutting edge best practices, and thoughtful discussion about end-of-life care. For more information on this informative conference, please visit [www.hpcanys.org](http://www.hpcanys.org)
- **AAIDD Annual Meeting – The New Professional: Leadership in Science, Practice, Policy and Advocacy** will be held in Washington DC from May 28-30, 2008. This is one of the largest national conferences dedicated to persons with developmental disabilities. There will be presentations related to end-of-life care, including a special professional workshop (extra charge for this ½ day workshop) on *Communication of Healthcare and End of Life Wishes through Person Centered Planning*. For more information or to register, please visit [www.aaidd.org](http://www.aaidd.org). Car-pooling opportunities from the Capital District may be available. For more information, contact [Anna Zendell](#).

### **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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