



E-Newsletter

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News

World Health Organization Issues First Ever Guide to Planning End of Life Care

The United Nations World Health Organization (WHO) just recently issued its first guide to planning for end of life care. This 51-page document was interestingly geared, not toward health professionals, but toward national health ministers around the world. Written primarily to aid countries in planning for burgeoning cancer-related deaths, this guide is helpful in preparing for any form of slow, painful death. To download a free copy of this guide, please visit: <http://dosei.who.int/uhtbin/cqisirsi/5pMfJp863r/19140006/9>

November is National Hospice/Palliative Care Month!

November is Hospice/Palliative Care Month, and this is a special time of awareness and outreach across our country to raise awareness on the needs of all people living with life-limiting illnesses! This is particularly true of all the unique facets of palliative care that provide enhanced quality of life for people for whom cure is not possible or likely. 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

Palliative care has become mainstream in our national news as well as academic journals. Here is a sampling of what has been in October's news.

A September 19th article in *JAMA (Journal of the American Medical Association)*, entitled Hospitals Embrace Palliative Care discusses the growing trend of treating chronically ill hospital patients using palliative care philosophies that embrace symptom management, communication and prolonging quality of life for patients and their families. The author, Bridget Kuehn, provides clear distinctions between palliative care and hospice services dedicated to people with terminal or life-limiting illnesses. This article can be useful in initiating discussions about integration of palliative care principles in settings such as hospitals—and other care facilities, such as those for persons with intellectual/developmental disabilities. For a copy of the article, please visit <http://jama.ama-assn.org>. If you cannot acquire the article, please feel free to contact Anna Zendell at ag0814@albany.edu, and request a hard copy.

The *Social Science and Medicine's* October, 2007 (Vol. 65, 7) issue featured an article entitled, What length of hospice use maximizes reduction in medical expenditures near death in the US Medicare program. This article, geared toward administrators of programs providing hospice-specific services, is very informative for its emphasis on hard data and its implications for administrators. If you cannot access this section, feel free to contact Anna at 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!

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 in direct response to a series of training workshops on palliative care and the ensuing demand for more information and collaborative opportunities. 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 in the near future. If you have a specific topic that you would like addressed, please let Anna Zendell know (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; seats are still available, though they are going fast!

- **Family Meetings: A Step by Step Guide for Palliative Care Teams** teleconference for professionals involved in palliative care service provision is being held on Tuesday, December 11, 2007 1:30-2:30pm EST. Call-in registrations are \$89 per line or \$99 for one line plus CD-ROM. Topics will include steps to effectively prepare, facilitate and document family meetings; practical strategies to address common communication challenges; and collaboration techniques between families and providers. For more information, please visit <http://www.capc.org/support-from-capc/audio-conf/>
- **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.
- **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 Here is just a sampling:
 - *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.