



Developmental Disabilities Hospice & Palliative Care

E-Newsletter

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I/DD Hospice and Palliative Care Issues

November is National Hospice and Palliative Care Month!

The theme for 2009, "*Preserving a legacy...treasuring memories*", reminds us that every palliative care and hospice patient is a unique individual with a lifetime of experiences, relationships and gifts to share.

Hospice organizations such as the National Hospice and Palliative Care Organization (NHPCO) and the [Hospice Foundation of America \(HFA\)](#) as well as hospice and palliative care agencies across the country are hosting events to increase awareness of palliative care and hospice. [NHPCO](#) has provided media talking points on their website that agencies or individuals can use to spread the word about hospice and palliative care on radio, newspaper, and television as well as a collection of articles that articles to those who may wish to learn more or to use them in hospice outreach and educational efforts. Remember, this is also an excellent time to focus on bringing awareness of the benefits of Hospice and Palliative Care to those underserved populations such as the Developmentally Disabled community.

October was National Disability Employment Awareness Month

In 1945 Congress designated each October as 'National Disability Employment Awareness Month (NDEAM). Every October since then, has provided us with the opportunity to celebrate the successes achieved by people with disabilities in the workplace. On October 5th President Obama Announced New Initiatives during National Disability Employment Awareness Month.

Following is a quote from that press announcement by President Obama:

"My Administration is committed to ensuring that all Americans have the chance to fulfill their potential and contribute to our nation. Across this country, millions of people with disabilities are working or want to work, and they should have access to the support and services they need to succeed. I call on all Americans to celebrate the contributions of individuals with disabilities to our workplaces and communities, and to promote the employment of individuals with disabilities to create a better, more inclusive America, one in which every person is rightly recognized for his or her abilities and accomplishments."

To read the entire press release and learn more about the specific steps the Obama administration is taking to assure that people with disabilities have unlimited employment opportunities, follow this [link](#).

To read the position statement from the **ARC**, regarding real employment opportunities for persons with an intellectual or developmental disability follow this [link](#).

In the News

How Will Health Care Reform Affect End-of-Life Care?

Health care reform has been center stage for most of 2009 and there is no doubt that end-of-life care and advanced care planning have been a focus across the country in the current reform debate. While there are many points of view, we wanted to provide links to a few articles and resources that will, if nothing else point out some of the key elements, important considerations and choices involved in end of life planning and developing a palliative care plan.

► On August 19th, the **New York Times** published an article well worth reading, entitled, [‘At the End, Offering not a Cure but Comfort’](#). This is a moving, thoughtful and necessary piece that illustrates both the benefit and the difficulty of introducing palliative care goals when a diagnosis of a terminal or life-limiting illness has been made. The article features Dr. O’Mahony, medical director of the Montefiore Medical Center’s palliative care service as he meets with and discusses the uncertain future of a cancer patient. Offering choices through information about available treatments that may ‘provide some local control, and slow the progression of the illness,’ and focusing on things he really can help with, like making sure that the patient has sufficient pain medication, Dr. O’Mahony also encourages the patient to be sure to have advanced directives in place so that her choices will be respected. If you would like to take the journey and read the article in its entirety, use the link above.

► On August 17th, **New York Times** Personal Health columnist, Jane Brody writes an article in which she highlights a book entitled [‘A Death Prolonged’](#) written by Dr. Jeff Gordon, a hospitalist physician from the Grant Medical Center in Columbus, Ohio. The book is a fictional account of situations that Dr. Gordon has commonly observed as a full-time doctor but is timely and applicable to the current debate over end-of-life care in the federal health care reform debate. In the introduction he writes: “Today’s high-tech medical care can sustain technical life — the beating heart — but utterly fails to restore real quality of life for many. There comes a point when physicians can prolong dying, but not provide quality living.” The author tells us that the stories are an attempt to tell the truth about end-of-life care in America and to promote awareness of end-of-life issues and thoughtful discussion of health care reform. If you would like to preview the book and read a few chapters use the following link: [‘A Death Prolonged.’](#) If you would like to read Jane Brody’s article click on the following link: [‘End-of-Life Issues Need to Be Addressed’](#).

► On November 12th the **Associated Press** published an article entitled [‘Few Americans make end-of-life wishes known’](#) which not only highlights the importance of assuring that advanced directives are in place for individuals of all ages but also points out that our culture doesn’t tolerate talking about death and dying well. The author discusses that fact in light of the ‘death-panel’ debates that arose in conjunction with the ‘Advance Care Planning Consultation’ provision in the original congressional bill. This article also describes the difference in patient outcomes between those patients who are able to make their treatment and advanced care wishes known and those who are not. Follow this [link](#) to read the entire article.

► **Engage with Grace 2009:** In consideration of the many family dinners that will occur over the next few days of the Thanksgiving holiday, for the second year in a row [PALLIMED](#), a hospice and palliative medicine blog (along with several other medical bloggers) is hosting a guest post from [Engage with Grace](#) and the [One Slide Project](#). At the heart of Engage with Grace are [five questions](#) designed to get the conversation started. They're not easy questions, but they are important...use the links above to read more about this project and to download the questions if you would like to bring them to your thanksgiving gathering.

Public Policy News / Advocacy Opportunities

► **The Arc of the United States**, through the work of their 'Governmental Affairs Committee', have established the [Disability Policy Collaboration](#), with United Cerebral Palsy, to focus on legislative, regulatory and legal issues at a federal level to work towards equity and equality for people with disabilities through public policy. This collaboration believes that long-term services and supports for people with intellectual and developmental disabilities must be included in Health Care Reform. Following are (2) proposed legislative acts that would provide these services and supports. Use the links below to learn more about each piece of legislation.

The Community Living Assistance Services and Supports Act (the CLASS Act)

Amends the Public Health Service Act to create a national, voluntary disability insurance program (CLASS program) under which: (1) all employees are automatically enrolled, but are allowed to waive enrollment; (2) payroll deductions pay monthly premiums; and (3) two-tiered benefits are provided, based on the level of disability, to purchase nonmedical services and supports that the beneficiary needs to maintain independence.

The Community Choice Act of 2009-2010 (S.683) amends title XIX of the Social Security Act to provide individuals with disabilities and older adults, who have a need for an institutional level of care, the choice of receiving their services and supports in their own communities rather than in an institution. This bill was reintroduced in March but still needs representatives to sign on as co-sponsors for the bill to have a chance of passing.

If you would like to ask your representative for their support on this legislation use the following link: [Federal Legislative Action Center](#).

► **The Trisomy-21 Translational Research Parity Act of 2009 or the 21 Act (S. 1762/H. 3656)** was referred to the Committee on Health, Education, Labor, and Pensions in October but needs additional co-sponsors to move forward in 2010. This is a bi-partisan bill intended to amend the Public Health Service Act in order to expand, intensify and coordinate programs of the National Institutes of Health (NIH) and the Centers for Disease Control and Prevention (CDC) and other Federal agencies with respect to translational research and related activities concerning Down syndrome. Specifically the legislation would:

- Create at least six Down Syndrome Translational Research Centers of Excellence that provide an optimal venue and infrastructure for patient-oriented research, and conduct basic, clinical, and translational research on Down syndrome.
- Establish a Down Syndrome Coordinating Committee to coordinate activities across the National Institutes of Health (NIH) and with other Federal health programs and activities

relating to Down syndrome.

- Develop a National Down Syndrome Patient Registry and Bio-bank that would provide clinical care; coordinate research and clinical activities and create a common data entry and management system for Down syndrome patient data collection and analysis. If you would like your representative to sponsor this bill, [Click here](#) to take action!

▶ **The NYS budget proposal for 2010** is currently under development by state agencies and the NYS Division of Budget. Although we all know that funding cuts are inevitable due to the current state deficits, Parent to Parent along with NYSRA, NYSARC, Catholic Charities, Parent to Parent of NYS, Parents in Support of Direct Support Professionals, Capital District Coalition, Self Advocacy Association of NYS and the Developmental Disabilities Association of Western New York and others have joined in a collaborative campaign urging Governor Paterson to include an increase for Direct Support staff in the 2010-11 Executive Budget.

These organizations are calling for a *'trend'* or base pay increase for those direct staff professionals caring daily for residents in community homes. *Trend factors* are one means of increasing wages and are a means of assisting service agencies to keep pace with inflationary increases. In the past, OMRDD has specifically targeted the use of trend factors by agencies for the recruitment and retention of direct support professionals, as well as to respond to other critical non-personal services costs.

If you would like to advocate for this trend or base pay increase in the upcoming Executive Budget you are asked to call, fax or write the Governor throughout the months of October and November. The phone calls and letters should be sent to the Governor in October, and November.

If you would like to add your voice to this effort, you can use the following link which will provide you with the appropriate contact information as well as a script that can be used when you call or write the governor's office:

[Support Direct Staff Trend Pay Increase in 2010](#)

[Information and Resources](#)

▶ **OMRDD Course Offering: [Surrogate Decision Making Program: Care & Compassion for Life - Withdrawal or Withholding Life](#)**

As many of you are aware, Article 17-A of the Surrogate's Court Procedure Act, also known as the Health Care Decision's Act has been amended to allow the Surrogate Decision Making Committee Program (SDMC) as a means to obtain informed consent for the withdrawal or withholding of life sustaining treatment. SDMC serves mentally disabled persons in facilities or programs licensed, operated or funded by the Office of Mental Retardation and Developmental Disabilities who do not have capacity to make informed treatment decisions and do not have legally authorized surrogate to act on their behalf. SDMC functions using specially trained volunteer panel members who review declarations regarding a person's capacity and appropriateness of the treatment decisions, then render a determination following a hearing.

OMRDD is offering a **2-hour program** that includes instructions on completing the SDMC

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application, guidance on how to present a case to the SDMC Panel and what to expect during the hearing. Some of the course objectives are to:

- Learn who can make the treatment decision on behalf of a patient
- Learn how to file a declaration for the withdrawal or withholding of life sustaining treatment on behalf of a person with mental disabilities
- Gain skills on how to prepare and present a case at a hearing

If you are interested in registering for this course or would like to review other OMRDD course offerings use the following link: [OMRDD Course Catalog 2009 - 2010](#)

► **National Disability Website Updated and Expanded**

In conjunction with the 19th anniversary of the Americans with Disabilities Act, the U.S. Department of Labor has re-named and re-launched the disability-information website. The new site, [Disability.gov](#) offers comprehensive information about programs and services, news and events as well as grants and funding opportunities from 22 federal and state agencies. It has been revamped with social media tools to encourage interaction and feedback, and new ways to organize, share and receive information. Visitors will be able to sign up for personalized news and updates, participate in online discussions and suggest resources for the site. New features also include a user-friendly way to obtain answers to questions on such topics as benefits, civil rights, community life, education, emergency preparedness, employment, health, housing and transportation.

It is definitely worthwhile bookmarking this site and sharing it with family members, employers, disability professionals, caregivers and just about anyone interested in disability-related information.

► **New study reports that genetic mechanism causing abnormal brain development and developmental disabilities may lead to new treatments**

The Institute for Basic Research in Developmental Disabilities (IBR), which is the research arm of OMRDD, has been conducting research into the causes of intellectual and developmental disabilities since its inception in 1968. The Institute contributed to a recently published study into the causes of intellectual and developmental disabilities, that found mutations in a specific brain enzyme upsets the normal balance of steroids in the brain and doom the brain to neurological problems later in life. Discussing the findings, IBR Director W. Ted Brown, MD, Ph.D., states that, "this is a completely new mechanism as no one had previously found such a genetic mutation of steroid processing in the brain leading to mental retardation...Future research could lead to new treatments and prevention of this cause of mental retardation." For those interested in reading the article follow this [link](#).

► **The American Academy of Hospice and Palliative Medicine (AAHPM)**

has created an informational website on palliative care and palliative medicine designed to "meet a growing need for information about palliative care and hospice as the population ages, and to address a lack of understanding about who can benefit from it." The site explains palliative care, what palliative care physicians do, the benefits of palliative care, when to seek hospice care, resources for caregivers, and a link to find a palliative care doctor.

Take a look at it here: www.palliativedoctors.org

► **The International Association for Hospice and Palliative Care (IAHPC)**

has announced the launching of **Pallipedia**, a free online palliative care dictionary to be built by the international community, under the auspices of IAHPC. Users may search for palliative

care terms, or submit definitions to be included in the dictionary; the dictionary can be found at: www.pallipedia.org

► The [Disability Resource Exchange](#) is an online community for people with disabilities. The website was the brain-child of Rudy, a 31 year-old man who has cerebral palsy and uses a wheelchair. His vision was to unite people with disabilities and bring them together in a vibrant community where they can share ideas and stories that will work to help and support others in the online community he built. We invite you to take a look at the site, other people with disabilities, the site is also recommended for those who care for someone who is disabled as it could help you get some insight into their lives and how they feel.

► Through research, policy analysis, training, and technical assistance, the [NY Makes Work Pay Project](#) provides policy and practice solutions to address New York State's estimated 70% unemployment rate among working-age people with disabilities. This initiative conducts statewide forums, regional networks and local trainings to help people with disabilities accumulate financial assets, access work incentives and advance their self-sufficiency. In order to provide continual education and opportunity, the organization not only provides ongoing educational opportunities but has also archived their webinar series, which include such topics as Plan for Achieving Self Support (PASS), the Medicaid Buy-In program, the Ticket to Work program, etc. To access these resource materials and others follow this [link](#).

Professional Development and Education

► **Book Review: WORKING WITH LOSS, DEATH AND BEREAVEMENT**
A Guide for Social Workers by Jeremy Weinstein

As a social worker myself, I can tell you -this is a book that makes you think. It covers the usual definitions and assessments of loss, the psychological aspects of loss and grief, and the skills, methods and theories of working with individuals and groups but it does so in a reflective manner. The text is enhanced with exercises, points for practice, case scenarios, and recommendations for further reading. There is a chapter on evidence, which discusses research mindedness, taking a step back to reflect on the validity of the assumptions that we carry with us and which underpin our day-to-day work. The last chapter deals with self-care, how we can deal with the personal, professional and organizational anxieties and other issues that arise in end-of-life work. Although written by a social worker for social workers, reading this book would be of value to any of the health care professionals in the palliative care team, both challenging and empowering them to reflect on what it is that we do. A review of the contents and sample pages are supplied by [Amazon books](#).

► **(CAPC) Center to Advance Palliative Care online campus featured course:**
[Hospital Cost Avoidance](#)

Establishing a solid financial base for your palliative care program is vital for start-up, growth and sustainability. Most programs are sustained through a combination of hospital support, billings, philanthropy and other sources. Of these, hospital support is the most important, especially at program inception, and most hospitals will only provide funding after clear financial justification is provided. CAPC's **Hospital Cost Avoidance** course will present the rationale and methodology of reductions in hospital costs as a result of palliative care interventions; review the foundations for obtaining financial support for a hospital palliative

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care consultation service and help you estimate consult volume for the first few years of operation.

To enroll in this course simply follow this [link](#) and remember, these palliative care e-learning courses offer you or the members of your team complete flexibility because they are available 24 hours a day, seven days a week. Logon and take the courses whenever you are available! CAPC is also announcing that their courses are now offered at the cost of **\$35** per course, per student.

**If you would like to learn more about CAPC, take a look at the other courses currently being offered, or learn about the Continuing Education Credits available, simply logon to:

[CAPC Campus Online](#)

► **NHPCO** announces their December 2009 Audio Web Seminars designed to provide your team with convenient, cost-effective learning opportunities that help them develop new insights, strategies and best practices to ensure the delivery of quality hospice and palliative care. Each month NHPCO brings nationally-recognized speakers to speak on interdisciplinary and leadership topics.

All NHPCO's Audio Web Seminars take place from 2:00-3:30pm EDT.

CE/CME's Offered: Counselor, Nurse, Physician and Social Work

December 10, 2009, Interdisciplinary Topic:

Professional Boundaries: Maximizing Care and Minimizing Stress

[Advanced Registration](#) Ends December 7th.

December 18, 2009, Leadership Topic:

**Creating an Organizational Culture that Embraces Hospice Values and Practices
Excellence**

[Advanced Registration](#) Ends December 15th.

Announcement

**Proposals are now being accepted for the 2010
Developmental Disabilities Hospice and Palliative Care
Forum Topics!**

The Developmental Disability Hospice & Palliative Care Forum is moving to a new platform and will resume again in January 2010. We are happy to announce that we are accepting proposals from professionals in the community who would like to host a forum discussion.



If you are interested in:

- ✓ Educating forum members on cutting-edge topics and ideas related to end-of-life care
- ✓ Highlight your programs on a statewide platform
- ✓ Presenting important research outcomes
- ✓ Networking with over 350 end-of-life health care professionals
- ✓ Gain recognition in the hospice and palliative care field

Then please [complete the RFP](#) and submit to HPCANY

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Upcoming Events ~~ Mark your Calendar

<p>The teleconference will be broadcast live-via-webcast and satellite on Wednesday, March 21st, 2010</p>	<p>Hospice Foundation of America (HFA) Announces the 2010 National Bereavement Teleconference - <i>Living with Grief: Cancer and End-of Life Care</i></p> <p>The teleconference will address care options related to cancer diagnoses as well as loss and grief reactions for patients, families and professional caregivers and examine psychosocial aspects of cancer, pain management, and ethical issues related to the disease.</p> <p>To participate: <u>Register online now</u> or <u>mail/fax your registration form.</u></p>
<p>May 13th & 14th , 2010</p>	<p>HPCANYS 30th Annual Interdisciplinary Seminar and Conference <i>Mission – Vision – Reality ... Celebrating 30 Years!</i></p> <p>This annual event promises to be as amazing and deeply thought provoking as in years past. It is designed to provide opportunities for networking, education, and thoughtful discussion about end-of-life care.</p> <p>This year HPCANYS is celebrating its 30th year of service!!! If you can make it, it's well worth the trip.</p>

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