



Developmental Disabilities Hospice & Palliative Care

E-Newsletter

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Reporting on I/DD Hospice and Palliative Care Issues

In the News

► **A July 15th New York Times article entitled, [‘Putting Patients at the Center of the Medical Home’](#)** describes what a patient-centered medical home is and why this model should deliver more efficient and better primary care to patients. The article then goes on to explain that early demonstration projects of this model of care which is premised on the strength of the doctor- patient relationship found that while the care teams (made up of nurses, medical managers, physician assistants and doctors) were enthusiastic and pleased with the results, the patients were left unhappy. The project found that patient satisfaction fell because while the providers were working hard to adopt the changes that were to benefit their patients, they had *‘temporarily lost their focus on the patients themselves.’* Additionally, few patients were cognizant of, much less involved in, the changes going on around them. In working so hard to adopt changes on their patients’ behalf, clinicians had temporarily lost their focus on the patients themselves. Use the title link above if you would like to read the entire article.

► **A July 13th article in the Washington Post entitled, [‘Health-care overhaul includes pilot program of house calls for elderly patients’](#)** discusses the 3-year demonstration project intended to test the efficacy of the ‘home-visit for chronically ill patients. The project called the ‘Independence at Home Program’ is scheduled to begin in January of 2012 and will enroll 10,000 patients on Medicare who are suffering with multiple chronic conditions, are unable to perform normal daily activities such as bathing and dressing and have been hospitalized or needed other high-cost care in the past year. The article points to the success of a similar program at the Washington Hospital Center called ‘Medical House Call Program’ to emphasize the potential of the new pilot. Gerontologist George Taler, who is the co-director of the program, says that since their program began 11 years ago they have served *‘roughly 600 patients, and have reduced expected hospitalizations among participating patients by almost two-thirds.’* Promising results such as these are causing supporters to try and push up the start date for the pilot program. Use the title link above if you would like to read the entire article.

► **A July 14th article in the NY Times entitled, [‘Rules Seek to Expand Diagnosis of Alzheimer’s’](#)** reports that medical experts are proposing a major change in the criteria for diagnosing Alzheimer’s disease. The changes are part of a new movement to diagnose and, eventually, treat the disease earlier. This is because researchers are now convinced that the disease is present a decade or more before the dementia presents, and treatment protocols should be developed and administered from the beginning of the disease trajectory. ‘Under the

new guidelines, for the first time, diagnoses will aim to identify the disease as it is developing by using results from so-called biomarkers — tests like brain scans, M.R.I. scans and spinal taps that reveal telltale brain changes.’ Dr. Paul Aisen, an Alzheimer’s researcher at the University of California, San Diego and a member of one of the groups who are formulating the new guidelines states that, “*Our thinking has changed dramatically...we now view dementia as a late stage in the process.*” Aisen is optimistic that the new guidelines have positive implications for all persons aging but for now, he said: “*We ought to be cautious that we don’t stimulate all this testing before we can give people something to manage their disease. There is no point in giving them just a label.*” Use the title link above to read the entire article.

► **The New Yorker, August 2nd article:** *Letting Go: What should medicine do when it can’t save your life?* This is a powerful, beautifully written, must read article that artfully uses a series of case histories and interviews with those involved to describe the reluctance of patients, family members as well as physicians to face and confront our own or our patient’s mortality. The article points out that people do have concerns besides simply prolonging their lives, that surveys of patients with terminal illness state that their top priorities include avoiding suffering, being with family, having the touch of others, being mentally aware, and not becoming a burden to others, but our system of technological medical care has utterly failed to meet these needs. Despite that survey, the facts are that nearly all patients think that time to let go will come later when there is nothing left to try and physicians are reluctant to stop trying. One physician recounts meeting with a young terminal patient who had undergone extensive curative treatment protocols and experimental procedures without success but was still hopeful. He states that in wanting to avoid telling her that additional treatment would be of no avail he instead “*raised with her the possibility that an experimental therapy could work against her cancers, which was sheer fantasy. Discussing a fantasy was easier—less emotional, less explosive, less prone to misunderstanding—than discussing what was happening before my eyes.*” The hard question we face, then, is “*how we can build a health-care system that will actually help dying patients achieve what’s most important to them at the end of their lives.*” One answer, the author points out, may be in extending the Hospice benefit in what is called concurrent care or Palliative care which allows patients to receive hospice services while not forgoing curative treatments.

If you would like to read the entire article and (I hope you do) use the following link:

[Letting Go](#)

► **An August 2nd article in the New York Times entitled, ‘[Feeding Dementia Patients with Dignity](#)’** discusses a new option that would negate the difficult and controversial choice of either providing nourishment or withholding it from Alzheimer’s and dementia patients who have lost the functioning part of the brain that controls eating. That option, called ‘palliative comfort feeding’ involves hand-feeding patients giving only as much as they will take and stopping if choking starts or the patient becomes agitated.

The article refers to a recent paper in ‘*The Journal of the American Geriatrics Society*’, in which author Dr. Joan Teno states that feeding tubes do not necessarily prolong life in patients with advanced dementia, and that surveys indicate a vast majority of nursing home residents say they would rather die than live with a feeding tube. Unfortunately, Teno goes on to acknowledge that, “*feeding tubes are used in about a third of all nursing home residents with advanced dementia, in part because the homes worry they could face regulatory scrutiny if their patients are losing weight*” and that “*hand-feeding can be time-consuming and labor-intensive.*”

Teno describes palliative comforting feeding as a humane method of preserving the patient’s dignity while providing human contact; “*Just imagine someone interacting with the patient, talking to them, cueing them into eating as opposed to someone walking to the bedside*

and pouring a bottle of Ensure down the feeding tube.” Use the title link above to read the entire article.

► **This August 4th article on the Slate entitled, ‘We Can’t Save You: How to Tell Emergency Room Patients that They’re Dying’** explores a new approach to emergency room care for patients who are being treated for a chronic disease(s) or a terminal illness. Author, Joanne Kenen describes the effort to bring a Palliative/Emergency medicine collaborative to the ER. This intersection of palliative and emergency care is described as a ‘patient-centered,’ approach that brings a deliberative goal-setting approach to emergency care for the seriously ill or the dying with the goal of improving symptom management, enhancing family support, and ensuring that the patient understands treatment options and the likely outcomes of their condition. The article highlights Emory University Hospital in Florida but also notes that in New York State at the Bronx’s Montefiore Medical Center, a palliative care nurse is now stationed in the ER, where many of the community’s poor receive their only health care.

According to Diane Meier, the director of the Center to Advance Palliative Care, having a palliative nurse in the ER is critical as, *“the first hours in the ER are when determinative decisions are made about disposition and plan of care, and palliative care could be contributing to those decisions ... Palliative care in the emergency department can shore up pain and symptom control and help the family marshal resources, whether the patient opts for the ICU, hospice, or something in between.”* The article goes on to explain that health care reform may be responsible for advancing the palliative/emergency medicine as many more pilot programs and partnerships will develop as health reform unfolds. If you would like to read the entire article please use the [title link](#) above.

► **In a July 11th article in the Huffington Post,** author Nancy Cronk tells us the very personal and honest story of her father’s end-of-life journey and how Hospice made a difference to both him and to their family. On making the decision to involve Hospice, Nancy writes, *“At the end of life, the very things we have always done automatically as a reflection of our love are in question. Logic is turned upside down. Feeding people who are dying, or giving medications to lengthen a life, can be cruel to a person who is suffering. Allowing someone you love to die naturally and with dignity is the hardest thing there is to do, and yet, it is also an opportunity for a final act of love.”* You can read this beautifully written, inspiring and informative story here: [My Father's Final Journey in Hospice](#)

Public Policy News / Advocacy Opportunities

► **Oregon Representative Earl Blumenauer** (D) has reintroduced a ‘revamped’ [Advanced Care Planning Bill](#) that would pay physicians for discussing advanced care planning with patients. The new bill allows for both Medicare and Medicaid to cover patients end-of-life conversations with their physicians *and* makes advance directives transferable between states. Dr. Robert Gluckman, Chief Medical Officer of Providence Medical Group’s Teaching Clinics who worked on the bill with Blumenauer states that patients who have end of life care planning are far less likely to die in an ICU setting and that their symptom control and their ability to communicate with their families is far advanced when they’ve had advance care planning.

► **NHPCO Hospice Action Network’s Legislative Action Center** (LAC) is an advocacy resource to connect with members of Congress. The congressional recesses and the 2010 Congressional elections are approaching soon; this is an excellent time to find out more about your Congressional representatives so you can be a more informed advocate. LAC is a comprehensive advocacy resource that is always available and accessible online where you

will find the '[Elected Officials](#)' section which provides you with the most up-to-date biographical information on your representatives as well as information on federal legislation and key votes, and a guide to brush up on your Capitol Hill basics. You can also use the following link to sign up for LAC alerts to keep updated on legislative activity and issues of concern to you:

[Hospice Action Network website](#)

► **New Group to Raise Cash for Disability-Friendly Candidates:** DisabilityScoop reports on the activities of a new Political Action Committee (PAC) called the 'Disability Power & Pride Political Action Committee' whose intent is to financially support political candidates who support disability issues. The group held their first fundraiser last month and plan on having another in September. If you are interested in learning more about the group and the candidates they are supporting or if you would like to join the action use the following link: [Disability Power & Pride PAC](#). You can read the article at: [DisabilityScoop](#)

► **Advocates Urge Congress to Address Growing Needs of Adults with Autism**

On July 15th, 2010 the advocacy group 'Advancing Futures for Adults with Autism' (AFAA) hosted a Congressional briefing in Washington, DC that brought together federal legislators, national policymakers and advocates for adults with autism (including individuals who have autism) to discuss priorities for action in the public and private sectors that address the increasing and unmet demand for effective services for adolescents and adults with the disorder; the AFAA estimates that more than 500,000 individuals with autism will enter adulthood in the next 10 years.

The honorary co-chairs of the Congressional briefing were Senator Robert Menendez of NJ and Congressman Mike Doyle of PA. The briefing included an overview of autism and the array of needs of adults on the spectrum. A stakeholder panel, featuring a diverse range of adults on the autism spectrum as well as family members, shed light on the strengths, challenges, complexities and humanity of those most intimately affected by the condition. Among a number of other policy recommendations, the group urged lawmakers to move forward with a previously proposed bill known as the [ABLE Act](#), which would allow Americans to establish tax-free savings accounts for people with disabilities much like those already in existence to help people save for college.

If you would like to view videos from the Congressional Briefing, including videos of each of the panels and remarks from the honorary co-chairs, Senator Robert Menendez and Congressman Mike Doyle, you can visit the [Congress Videos](#) page.

► **NYS Partners in Policy Making** is an innovative national model of leadership training for people with developmental disabilities, self-advocates and parents/family members of individuals with developmental disabilities. It is designed to provide state-of-the-art knowledge about issues and policies related to disability, and to develop participant competencies to become more effective in influencing policy development at all levels. The overall intent is to achieve a productive partnership between people with developmental disabilities, parents, and family members, and those in position to make policy. The Developmental Disabilities Planning Council, the Employment and Disability Institute at Cornell University and the Advocacy Center have joined forces to design, implement and evaluate the Partners Program delivery.

If you would like to learn more about this opportunity or submit an application for 2011 use the following link ~ *Note that the application deadline is September 15th 2010!*

[Partners in Policymaking](#)

► **President Obama Signs Bill Ensuring Funding For Independent Living Centers**

On July 29th, 2010 the president signed new legislation into law that was designed to close a loophole and provide adequate funding for independent living centers across the country which would offer services to individuals with disabilities. The '[Independent Living Centers Technical Adjustment Act](#)', originally sponsored by House Representative George Miller of California, ensures that independent living centers for disabled adults receive sufficient federal funding. The [Hills Healthwatch](#) reports that the new legislation came in response to a funding disparity which emerged as a result of last year's stimulus package, leaving some independent living centers eligible for far more money in future years, while other centers would be underfunded.

[Information and Resources](#)

► **The ARC's Family and Individual Needs for Disability Supports (FIND)** is conducting an online survey to capture the knowledge, perspectives and perceptions of individuals with intellectual and developmental disabilities of all ages and their families on issues concerning disability support needs across the life spectrum. They are asking all leaders and professionals in the disability sector to pass along the opportunity to take part in this survey within your local communities, to your networks, to self-advocates, and to all the families and caregivers who are the recipients of your hard work and dedication.

This is a meaningful way to involve individuals with intellectual and developmental disabilities (I/DD) and their families in understanding services needed, provided and desired. It is important to note that respondents' answers will remain completely anonymous and confidential and that their identity will remain unknown to staff working on this project unless they should choose to make that known. The results from this confidential survey will provide greater understanding about what services are available, what gaps exist and what new supports are needed. Please use the following link to access the survey site and provide this link to individuals who wish to participate: [FINDS Survey](#)

► **The Alzheimer's Project:** While currently there is no known cure for Alzheimer's dementia, the results of recent research are raising hopes that it may be possible to delay its onset, slow its progress, or even prevent it altogether. The studies detailed in the Alzheimer's Project indicate that delaying the time when symptoms begin by even 5 years could greatly reduce the number of people who have this devastating disease. The National Institute on Aging (NIA), part of the National Institutes of Health at the U.S. Department of Health and Human Services teamed with HBO to present a series of documentaries called the [Alzheimer's Project](#), which discussed recent research results regarding risk factors, preventative strategies such as nutrition and early diagnostic procedures. You can view all of the HBO documentary films using the title link above. The content of these documentaries have also been summarized in print by the National Institute on Aging (NIA) and offered as a publication to the public; you can download the 36 page document here: [Can Alzheimer's Disease be Prevented?](#)

► **A July 7th article published in the Boston Globe** discusses a program called 'End of Life' at Harvard Medical School. The End of Life program uses the ancient Greek tragedies to "*spark discussion among medical students and professionals about the ethics of treating patients facing painful, prolonged deaths.*" The 90 minute program that professors, doctors and students have all taken part in is described as "*raw, honest theater and emotional discussion add a dimension of reality to medical ethics education that textbooks cannot.*" As medical technologies extend the lives of the sickest patients, medical schools across the country have struggled to find a way to help doctors better navigate new moral quandaries around death and

dying. The recent performance of scenes from Greek plays at Harvard Medical School represents one of the more unusual and emotionally powerful approaches. At Harvard Medical School actors are performing these scenes from ancient Greek plays as “*a way to help doctors better navigate new moral quandaries around death and dying.*” If you would like to read this very interesting article use the following link: [Drama animates issues in Harvard ethics course](#)

► **180 Days** is a one-woman play that tells the story of Taren Sterry’s experiences during her first six months as a hospice volunteer. Sterry is a writer and performer in NYC and the Manager of Volunteer Program Services at the Visiting Nurse Service of New York Hospice Care. Taren not only wrote the play but performs as she takes the audience on her hospice journey. Her play, 180 Days, has been running since September 2009 and is touring around the country. The story begins while Taren embarks on a six month ethnographic field study to work with terminally ill patients and their families; she tells of how she eagerly anticipates having deep spiritual encounters with her patients, but soon learns that if she is to be successful she must first learn how to survive in a foreign land, face the past and savor the taste of humble pie. Not sure what to think? You can watch a 5-minute preview of the show at [YouTube: 180 Days](#) If you’d like to learn more or book Taren to perform please visit her website at: [180 Days](#)

► **Regal Cinemas creates a friendly environment for the developmentally disabled community.** On the 2nd Saturday of the month Regal Cinemas of Medina, in conjunction with the Medina Center Therapeutic Arts and The Medina County Board of Developmental Disabilities, presents the “My Way Matinee.” These matinee showings have the lights turned up, the sound lowered and movie goers are free to move around. This has helped many families be able to take their child to a movie where they may not be able to go before, because they no longer have to worry about their child wanting to move around. No reservations are required, for more information contact the Medina Regal Cinema office at 330-721-7056 or Jeff Burlingame at the Medina Center of Therapeutic Arts at 330-721-9695.

Professional Development and Education

► **Spirituality in Palliative & End-of-Life Care:** an educational training module developed for healthcare workers and chaplains that is specific to palliative and end-of-life care. Created in 2003 by Hillel Bodek, MSW, LCSW-R, BCD, the module was originally developed to train chaplains and community clergy to integrate spiritual care services into the fabric of palliative care as co-equal services along with those services which address the physical and psychosocial needs of patients in palliative care. Hillel then went on to include training to facilitate the ability of physicians, nurses, social workers, psychologists who work in palliative care, to perform spiritual assessments and provide interventions to address spiritual issues/concerns/crises in the absence of chaplains trained in palliative care. Hillel is passionate about the importance of both the palliative care and faith/religious communities coming together as a group to energize a nationwide movement and bring spiritual care to its rightful, critically important place in palliative care's core mission to treat total pain.

This educational training module along with the accompanying pre-tests and post-tests, power point presentations, spirituality questionnaire for clergy as well as a questionnaire for health care professionals is available for FREE on the ‘[Growthhouse](#)’ website. If you are interested in having your staff trained in conducting spiritual assessments you may access the curriculum using the following link: [Spiritual Care at the End of Life](#). If you are interested in providing training in palliative and end-of-life care for community clergy including lay people

who assist the clergy in addressing the needs of homebound ill, persons, contact Hillel directly at: bodekmsw@verizon.net

► **Secretary of Health and Human Services Kathleen Sebelius** announces Healthcare.gov a website that is intended to be tool for consumers to understand the provisions of the new *Affordable Healthcare Act*, and to find health insurance/provider Information. If you would like to view the video announcement, [click here](#).

The site is a one-stop-shop that gives consumers the ability to see all their public and private health insurance options in one place for the first time ever, and is also set up so users can enter their individual information and see the plans offered in their community that make sense for their situation. Currently, it is already loaded with data from more than 1000 insurance carriers in addition to government programs like Medicaid and Children's Health Insurance Program (CHIP). You may also take a video tour of the site; this is a 4-minute tutorial that is helpful to view before you navigate the site ~ to take the tour, [click here](#).

► **Book Review: Handbook for Mortals: Guidance for People Facing Serious Illness** by Joanne Lynn, M.D. and Joan Harrold, M.D. This book offers very useable advice about options at the end of your or your loved one's life, yet is filled with remarkable poetry, photos, and anecdotes to have an emotionally positive impact on readers struggling with these issues. It is not a book to use only when the end is near; it is a book that offers practical information, instruction, tools and instruction to help you, a loved one or a patient with End of Life concerns *and* how to plan for them. So often, a crisis situation occurs that does not allow you the opportunity to discuss critical issues with your family. This book will provides the necessary tools to discuss your wants and wishes for the living of your years.

*** The book can also be read online ***

You can access the online edition at: [Americans for Better Care of the Dying](#)

~~ Author and physician Joanne Lynn also gave testimony before the Senate Special Committee on Aging on many of the key issues in end-of-life care found in the book. Included in her testimony are statistics on death trends, suggestions for immediate action, and tips for health care providers on how to approach end-of-life discussions with patients. If you would like to download the transcript of Dr. Lynn's testimony along with the accompanying attachments including: *Promises to patients; Twenty things clinicians could do; Getting started—improvement activities for providers; The Agitator's Guide*, use the following link:

[Dr. Lynn Senate Testimony](#)

► **Being with Dying: Professional Training Programs in Contemplative End-of-life Care** not only offers a unique program that provides clinicians with essential tools for taking care of dying people with skill and compassion, the program also addresses the need for healthcare providers to develop knowledge and skills in the psycho-social, ethical, and spiritual aspects of dying. The program offers an approach to caregiving that is relationship-centered, including community development and cross-cultural issues as well as the development of skills related to care of the caregiver and the means to implement these skills in traditional medical settings. For practitioners specializing in end-of-life care this is an opportunity to learn skills and techniques that are not generally addressed in the current training of physicians, nurses, psychologists, social workers, and other healthcare providers, and is essential in the care of dying people.

If you or your organization are interested in learning more about this training, or if you just want to review relevant articles or browse the educational and informational books and/or videos offered there, use the following link: [Being with Dying](#)

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

The Developmental Disability Hospice & Palliative Care Forum has moved to a new platform and will resume again in 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
- ✓ Highlighting your programs on a statewide platform
- ✓ Presenting important research outcomes
- ✓ Networking with over 350 end-of-life health care professionals
- ✓ Gaining recognition in the hospice and palliative care field

Then please follow this link to [complete the application](#) and submit to HPCANYS, or email me at kconnell@hpcanys.org

Upcoming Events ~~ Mark your Calendar

<p>September 20th, 2010 OD-Heck Bldg 10 500 Balltown Rd Schenectady, NY 12304</p>	<p><i>The Dad's Place At Parent to Parent of NYS</i> Dads Place is where Fathers of Children with Developmental Disabilities or Special Health Care Needs meet to Connect with other Great Fathers for Outstanding Conversations and Networking</p> <p>Septembers meeting features Brian Sheridan from the Bus Stop Club on the topic of 'Siblings of children who have a Disability'</p> <p>Please RSVP to Jim Swart by September 13th at: jmswart1@verizon.net</p>
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<p>October 21-23, 2010 Pointe Hilton Tapatio Cliffs Phoenix, AZ</p>	<p align="center">CAPC National Seminar <i>Building New Paradigms in Palliative Care</i></p> <p>New York State hospitals, and hospices with an established hospital palliative care program partnership, are eligible to register at no cost. This funding is made possible by a grant awarded to CAPC from the New York State Health Foundation. Space is limited, register early!</p> <p align="center">Early Bird and Special Rates are Available through September 15! Learn More and Register at www.capc.org/seminar</p>
<p>September 1st 2010 Hospice of Central NY Liverpool NY</p> <p>September 28th, 2010 Bronx VA Medical Center Bronx, NY</p>	<p align="center">Hospice Veteran Partnership Educational Cooperative <i>Hospice Veteran Partnership Training Workshops</i></p> <p>The VA Health Network Upstate NY & HPCANYS are presenting (2) trainings targeted at Palliative Care Consult Teams and Hospice Veteran Partners. One training will take place in Brooklyn NY and the other in</p> <p align="center">♦ CEUs for Physicians, Nurses and Social Workers will be provided. ♦</p> <p align="center">FREE registration for all Hospice, Palliative care & VA staff</p> <p>For more information go to HPCANYS calendar of events or click on one of the dates to the left.</p>
<p>September 17th, 2010 Desmond Hotel & Conference Center Albany, NY</p>	<p align="center">ProCare HospiceCare 5th Annual Conference <i>For Hospice Clinicians, Administrators and CFO's</i></p> <p>This educational conference is FREE to all hospice & healthcare professionals!</p> <p><u>Sessions Include:</u></p> <ul style="list-style-type: none"> ♦ Therapeutic Update-Hospice Empiric Opioid Utilization and the New FDA "REMS" (CE available) ♦ The Comprehensive Management of Nausea and Vomiting (CE available) ♦ Tales from the Bedside ♦ Future Competitive Environment for Hospices <p align="center">You can register online at: ProCareRx.com (Just scroll down and look for the waving sunflowers on the left) Or Call 800-377-1037 Ext.4754 for more information</p>

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