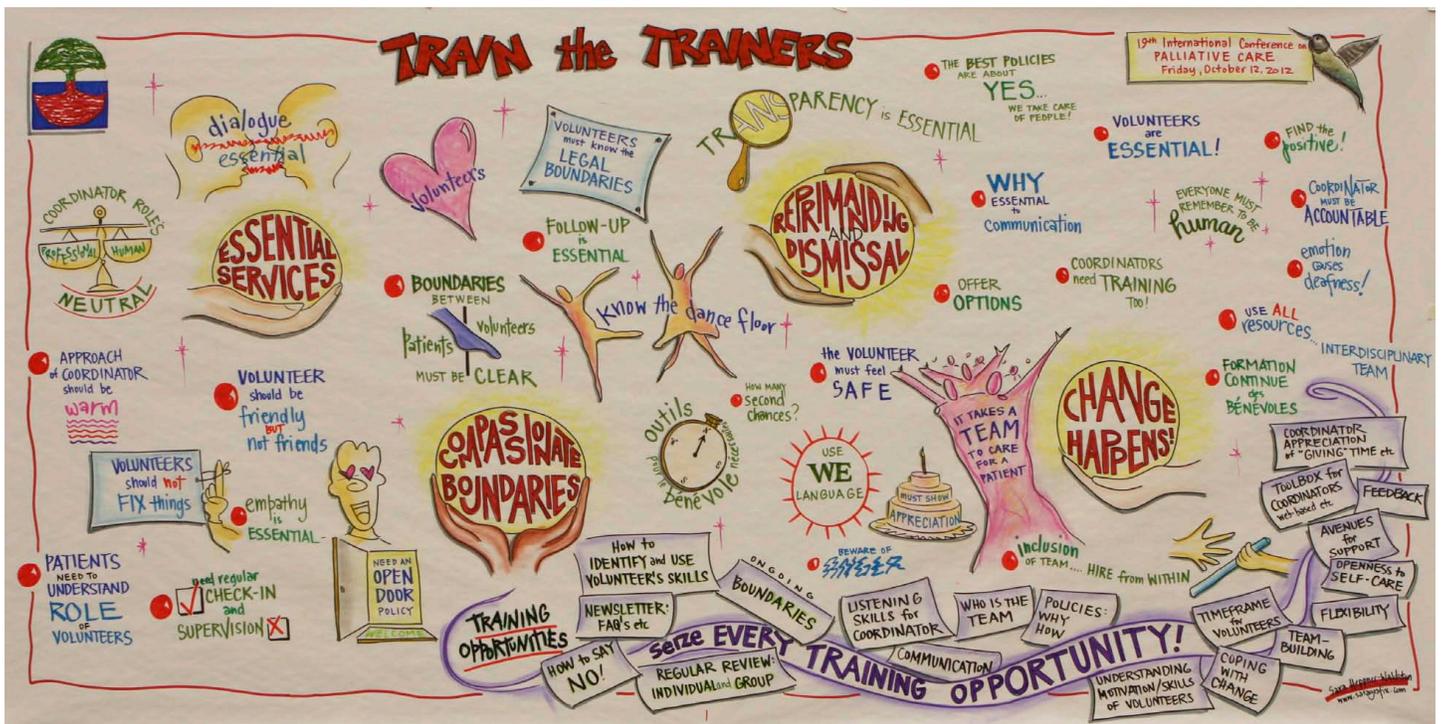


National Hospice
Palliative Care Week
May 5-11, 2013

Sandra Goldberg Lecture
Tuesday, May 7, 2013

The Council on Palliative Care

Turning Good Intentions into Good Work: Skills Development for Volunteers and Coordinators in Palliative Care



As part of its mandate to provide community education in palliative care, the Council on Palliative Care developed a second series of training videos, with an accompanying manual, for volunteers, coordinators and healthcare professionals. The videos focus on some of the common challenges Volunteer Coordinators experience in their working relationships with volunteers and were created in response to the interest generated by the first video series, presented in 2008 at the 17th International Congress on Palliative Care. The goal was to increase and share knowledge of best practices in volunteer management and to foster dialogue on challenges and strategies for providing support to volunteers in their care of patients and families.

The workshops were presented in two 90-minute segments. They were open to professionals and volunteers interested in dialogue, learning, information and exchange of ideas around the issue of integrating volunteers as full partners in their programs. The four videos at the core of the workshops highlight common challenges that Palliative Care Volunteer Coordinators in urban and rural, hospital and community settings encounter in recruiting, training, supervising and admonishing volunteers.

The workshops were a resounding success! There were approximately 120 people in attendance at each of the two workshops. Participants were broken into

Continued on page 3

The Council on Palliative Care is a non-profit organization that was established in 1994. The objectives of the Council are to increase public awareness, public support and availability of palliative care within and beyond the McGill University Health Centre (MUHC) network. It pursues these objectives by working with healthcare planners, educators, practitioners and the community at large.

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The Living Will

By: Michael Dworkind, MD

Where there's a will ... there's a way."

"Preparing your Living Will can help your family through a difficult time of decision-making."

End-of-life decisions are often difficult, and unfortunately, arise in the last days or weeks before death occurs. In these circumstances, the literature shows that patients may not be competent to discuss their preferences and families are too distraught and stressed to be able to respond in an appropriate fashion. The evidence also shows that families do not always reflect the values and preferences of their loved ones. Physicians have been known to write 'do not resuscitate' orders (DNR) without always knowing the wishes of the patients. This is often the case if the patient is either incompetent or cannot speak for him or herself.

The Living Will, or Advanced Directive, as it is also called, is a document which tries to address this problem. If done when adequate discussion and reflection are possible, the best decisions about end-of-life care can be made. To optimize this process, the discussion should be held with those individuals who have been appointed mandataries or substitute decision makers and any other family members deemed appropriate. Primary care physicians and specialists, who provide hospital care and who will ultimately depend on these decisions to guide them in their life-sustaining interventions, (e.g. CPR) should also be involved. These critical interventions are the first step in deciding whether prolonging life is the goal, or

on the other hand, if palliation is the goal -- which is where comfort and dignity take over from life-prolongation. This is especially true when that life has become too burdensome and filled with suffering.

Many hospitals have policies that encourage discussion about end-of-life care. The catalyst for these discussions can be the Living Will. It becomes a powerful medical and legal tool if the mandataries, armed with the document, advocate for their loved ones in an appropriate and caring fashion.

Thus, the purpose of having a Living Will is to make your wishes known regarding health care decisions to be taken at a time when you are critically ill and may lose your decision-making capacity.

Completing a Living Will or an Advanced Directive is a tool to open up sensitive discussions with your families and professional caregivers at a time when you can most clearly address these issues. It can help facilitate a dialogue between you, your physician, and your family about the specific types of care and life-sustaining treatments you would like to receive.

Most Living Wills are completed in a notary's office when doing estate planning. Only the Mandatary section is legally binding in Quebec. However, a Living Will does not require a lawyer or a notary to be completed. Having it signed in front of two witnesses is sufficient.

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The Living Will (cont...)

(From page 2)

Living Wills are rarely reviewed by the physicians who ultimately make the end-of-life care decisions. It is therefore better to speak to your family, and then discuss this with a physician whom you know and trust. This discussion is an important part of the Living Will process. The person you choose to make decisions on your behalf (your mandatory) will gain a clearer understanding about your choices, as well as your feelings.

I believe that the discussion is more important than the document. The document acts as a framework to guide the discussion but ultimately it is the mandatory, or substitute decision maker, who have the responsibility to speak for you when you no longer can. They will use the Living Will document in ways that best advocate for your care. Completing and updating your Living Will will help to reduce the burden on family and caregivers. It will enable them to respect

your end-of-life decisions --in keeping with your values.

Whether you use the form available from your notary or another, it should be distributed widely. It should be included in your family physician's charts and your hospital charts.

The Jewish General Hospital Living Will document is available on line if you wish to use it to enhance end-of-life care planning.

English version: www.jgh.ca/departments/clinical_ethics/index.html

French version (Testament de vie): www.jgh.ca/departments/clinical_ethics/ce_intro_f.htm

Dr. Michael Dworkind is an Associate Professor of Family Medicine at McGill University. He is the Director of the Palliative Care Consult and Home Care Service and Director of the Living Will Project at the Jewish General Hospital.



"There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers."

Rosalynn Carter



Turning Good Intentions into Good Work (cont...)

(from page 1)

10 groups to facilitate discussion and the sharing of ideas. Nursing students from Dawson College acted as scribes for each group. They then reported the salient points to everyone. They were amazing!

The videos and the discussions they generated, enabled participants to reflect on their practices and enhance their skills.

Graphic artist, Sara Heppner-Waldston, did a 'graphic recording' of the workshops. The "map" she created is a great visual summary of the workshops and a great training and discussion tool, in its own right. (see front page)

Both sets of training videos (Series I and II), the training manuals and the 'maps' are available for download on the Council's web site, for use as teaching tools. (www.council-on-palliative-care.org).

Events & Happenings!..

16th Annual Sandra Goldberg Lecture - May 7, 2013

The 2013 Sandra Goldberg Lecture will feature Will Schwalbe, author of *The End of Your Life Book Club*, in conversation with Louise Penny.

This year we will focus on the family and the lay person and after hearing Mr. Schwalbe's recent interview on CBC radio, we felt he would be an excellent speaker for our *Lessons in Living from the Dying* series.

The End of Your Life Book Club was written by Mr. Schwalbe after caring for his terminally ill mother. As Patricia Crowe says in her review of the book in The Gazette (November 23, 2012),

"Schwalbe gives us so much more than a portrait of a dying woman who had a remarkable life. It is as much a love letter to his mother as it is to reading. 'We didn't read only 'great books',' said Schwalbe, *'we read casually and promiscuously and whimsically.'*

Their book club meets mostly in the waiting room at the Memorial Sloan-Kettering outpatient centre in New York while they wait out her chemo treatments. The chapters are named for one of the books they discuss, but that one book always leads to a wealth of others; the appendix is a six-page list of the authors and stories they talk about. And Schwalbe, an editor and publisher, knows what constitutes a good précis. He makes all the books referenced, whether he liked them or not, sound worth reading."

With his book Mr. Schwalbe reminds us, once again, how many ways there are to care for a loved one who is terminally ill.

Louise Penny is a former CBC journalist and a world renowned author of the Chief Inspector Gamache novels. Her latest is, *The Beautiful Mystery*. She has won North America's prestigious Agatha Christie Award an unprecedented four years in a row, and the Anthony Award for Best Crime Novel in the U.S. for three years running.

This free public lecture will be held on Tuesday May 7, 2013 in the Leacock Building at McGill University, Room 132, at 5:30.

A reception and authors' book signing will follow the lecture.

David Bourke Memorial Lecture

On October 9, 2012 as part of the 19th International Congress on Palliative Care, the Council held its Annual David Bourke Memorial Lecture.

"**Dying at Home: A Choice**", was the title of a staged reading of excerpts from, *Home Death*, a play written by award winning British playwright, Nell Dunn.

In the play, Nell Dunn explores the complicated choices one must make when choosing to die at home, through her own experiences and those of others who have made the same decision. In this unflinching look at their experiences, she shows what worked for each of them and what did not. It raises questions about how we should be supporting people who choose to die at home, and their families.

This staged reading was performed by actors who are either practicing, or studying to be, drama therapists. The three vignettes read were *Dan and Nell*, *Trevor and Lesley* and *Diana and George*. The actors, Jennifer Finestone, Carrie Foster, Lois Jones and Simon Driver were superb and it was very well received by the audience.

Each reading was followed by a panel discussion. The panelists were, Sue Britton, a Palliative Home Care Nurse, Zeldia Freitas, a social worker and clinical supervisor at CSSS Cavendish, Anita Mountjoy, a nurse and family caregiver and Dr. Golda Tradounsky, a Palliative Care Physician. The evening was moderated by Jo-Ann Jones, a nurse-educator in palliative care.

The lecture was open to the general public and there were doctors, nurses, social workers and volunteers from the 19th International Congress on Palliative Care in the audience.

The evening was videotaped and is available on our website, www.council-on-palliative-care.org.

The topic and material presented highlights an important, yet greatly overlooked, topic.

Gift Giving on the Palliative Care Unit

By Delores Nickerson, Palliative Care Volunteer and Founder of the Gift Giving Program

We have learned that simply because a patient is pre-occupied with dying does not mean that he or she no longer has the energy or emotional need to celebrate special events such as Christmas. Quite the contrary, special events may take on new importance and new meaning to these patients.

Christmas giving by patients to their caregivers has evolved naturally over the years. In 1987, we felt that caregivers would benefit by receiving gifts from patients. We chose the gifts very carefully to ensure that they were appropriate in the circumstances. We helped the patients wrap the gifts and write the cards. Through this process, we observed that the patients were enthused about giving. It gave them an interest in Christmas itself. In one case, no sooner had the gift been wrapped the patient said: "Could we please unwrap the gift as I will want to look at it often". One caregiver in bereavement often commented: "The gift I received from my brother has touched me more than you will ever know. I get such a warm feeling every time I see it, it is precious to me in the most joyful sense."

In the months following the first Christmas of giving, we began to collect a variety of gifts for the next Christmas.¹ We decided to set up a gift cart to enable patients to do the Christmas shopping themselves. If the patient was too ill to participate, we invited a family member to select the gifts. "Christmas shopping" was done about one week before Christmas. When patients enquired about the cost, our answer was "hugs please!"

Words cannot do justice to the excitement, love, thoughtfulness and serenity which was part of each encounter. One patient, in pondering the many gifts available, said: "I don't want anything that he will have to dust. I'd like to give my husband this box of linen handkerchiefs." Some months later, a volunteer spoke to that patient's husband following the memorial service on the Unit. Weeping, he said: "My wife gave me this handkerchief you know. I feel that she is with me when I cry and it helps". The volunteer was pleased to tell him the story behind his wife's choice.

As part of Christmas giving, we also gave each patient a Christmas stocking at their bedsides to awake to on Christmas morning.² It was a patient who taught us the importance of this tradition. Early on Christmas morning, a normally very reserved patient

anxiously rang for this nurse. With a childlike twinkle in his eye, he said: "Quick, take me to the solarium – you never know what Santa has left under the tree". The poor nurse, knowing there was nothing there, rushed out to the nurses' station and asked a nurse to quickly gather a few items to put under the tree. The patient soon realized why the nurse had acted hastily and the magic of Christmas was lost to him. We thank this man for teaching us the importance of letting the child within participate in the tradition of Christmases past.

Patients are encouraged to give as many gifts as they please to family members and friends. Sometimes, this can number in the twenties. One patient, who did not have many family members, chose gifts to have available for visitors who had been supportive.

We have decorative bags, fancy containers and tissue paper to allow easy access for frequent viewing ... and the hugs are never ending!

More than ever we believe that giving is an essential part of living!

¹ Examples of items on the gift cart: stuffed toys, candles, handkerchiefs, scarves, window bird-feeders, toiletries, candy, picture frames, ornaments, novelty items, games.

² Two ladies have volunteered to provide 16 handmade stockings for our patients on the Palliative Care Unit. The stockings are then filled with such items as lip balm, assorted herbal teas, moisturizing lotion, home-baked jellies, a fun item, candy, a Christmas ornament, etc. Christmas stockings can be made up in October and then set aside. This prevents Christmas overload.



Donations of gifts, or money to purchase gifts, may be sent at any time, to:

**Sandra Watson, Bereavement Program and
Volunteer Coordinator
Palliative Care Service
Montreal General Hospital
1650 Cedar Avenue, Room E10.116
Montreal, QC
H3G 1A4
Tel.: 514-934-1934 ext. 43810**

19th International Congress on Palliative

This past October, Palliative Care McGill once again hosted a very well-attended International Congress on Palliative Care. With over 1600 participants from 56 countries, over 700 abstract submissions, and a larger programme than every before, this 19th edition of the Congress was record breaking. A great new feature of this Congress was the live web-streaming of the four plenaries and a few other presentations to several developing countries. With support from some key sponsors, this international outreach and exchange will become a regular part of the Congress.

Thanks to the hard work of the Congress Chair, Dr Anna Towers, and the executive and programme committees, this year's scientific programme was especially rich. Over 55 invited speakers from 10 different countries spoke on a wide range of issues. The four plenaries alone included presentations on stress and coping, dignity, the evolution of pain treatment, team resilience, and suffering. The closing plenary, given by the esteemed Dr. Balfour Mount, focused on openness, self awareness, and radical presence as key to healing. (Exceptionally, Dr. Mount's plenary is available for purchase at www productionsboulevard.com). The early morning research forums were equally rich with presentations on end-of-life protocols; family physician's patterns of end-of-life care; perinatal palliative care; adolescent caregivers; and advanced kidney disease, among others. Finally, in addition to its traditional subject

streams (e.g., pediatric palliative care; nursing issues; education; ethics; family caregivers; volunteers), the scientific programme featured special sessions on neurodegenerative disease, pharmacotherapy, and palliative care in Japan.

What makes the International Congress on Palliative Care exceptional is not just its rich scientific programme, but its not-so-little extras such as the quiet-time spaces, the film-screenings, the social programme, and the David Bourke Memorial public lecture. A labyrinth, a meditation room, and on-site massage were amongst the many ways that the Congress valued quiet reflection and decompression. Three lunch-hour film screenings offered global perspectives on end-of-life care. An evening of lively music at Montreal's Metropolis attracted 600 participants who cut loose to the tunes of the Celtic Rhythms. The David Bourke Memorial public lecture provided moving theatrical representations of the end of life issues that arise for patients and their family caregivers in the context of the home.

If you missed out on this rich 2012 experience, be sure to book time for our 2014 Congress. A celebration of both the Congress's 20th birthday and 40 years of palliative care at McGill University. The next Congress (Sept 9-12, 2014) will reflect on the past and look to the future to create a programme that is not to be missed!

THANK YOU TO OUR SPONSORS IN 2012

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