

# Council on Palliative Care

**Palliative Care  
Week 2004  
May 3 to 9**

*"You matter because you are you.  
You matter up to the last moment of your life,  
and we will do all we can,  
not only to help you die peacefully,  
but also to live until you die."*

*Dr. Cicely Saunders*

*(the pioneer of the modern Hospice movement)*

## *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 facili-

tate 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 Mandatory 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.

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 mandatary) 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 mandatary, or substitute decision makers, who have the responsibility to speak for you when you no longer can. They will use the Living  
*Continued on page 2*

*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 health care planners, educators, practitioners and the community at large.*

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## Book Review by Richard L. Cruess, MD

### *“Caring for Loved Ones At Home”*

The Council on Palliative Care has been extraordinarily fortunate to have been able to acquire *“Caring for Loved Ones at Home”* by Harry van Bommel. This wonderful book, which has been published by the Saint Elizabeth Health Care Foundation, was created to “help people who need extra health care support at home.” While the book is intended to provide support for those caring for patients with a wide variety of medical conditions, it is particularly appropriate for those interested in palliative care. The Council has arranged for its translation into French and will make either version available to those who need it.

The book is a wonderful fount of information and advice to those providing support at home. It is written in such a clear and simple style that one tends to overlook the great wisdom contained in its pages. It is something from which, quite literally, everyone can learn something, but for those in need can truly be described as a Godsend.

Its chapter headings are instructive. “What To Do In An Emergency,” “Home Care Examples,” “Understanding How Illness Affects You And Your Family,” “Adapting Your Home And Getting The Right Equipment,” “Home Care Suggestions,” “Family and Friends: Visiting Someone

Who Is Ill Or Recovering,” “Good Nutrition,” “Talking With Your Doctors And Other Caregivers,” “Understanding Your Condition,” “Creating Your Own Support Team”.

The section on “Basic Care” is, of course, the core of the work. It is a mixture of quietly inspirational writing (the section on “The Mutual Gift of Caring”) and extremely sound and simple advice. It spends time on infection control, advising all who deal with the ill to wash their hands well and to use masks when appropriate. It offers advice on assistance with ambulation. The sections on “Personal Care” and “Bed Care” are outstanding. Finally, there are sections on pain and symptom control which, once again, are extraordinarily sound in both their explanation and in the actions recommended.

Mr. van Bommel has created a wonderful resource for those who need it and the Council is extremely grateful to him and to the Saint Elizabeth Health Care Foundation for making it available to us and for allowing us to translate it so that it may reach a wider audience.

For those interested in obtaining the book, it can be found on the Web at [www.legacies.ca](http://www.legacies.ca) (in English) and at [www.med.mcgill.ca/orgs/palcare/copchome.htm](http://www.med.mcgill.ca/orgs/palcare/copchome.htm) (in French), and is available from the Council on CD Rom.

## *The Living Will* (continued from page 1)

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 physicians' 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](http://www.jgh.ca/departments/clinical_ethics/index.html)

French version (Testament de vie):

[www.jgh.ca/departments/clinical\\_ethics/ce\\_intro\\_f.htm](http://www.jgh.ca/departments/clinical_ethics/ce_intro_f.htm)

Dr. Dworkind is an Associate Professor of Family Medicine at McGill and the director of the Living Will project at the Jewish General Hospital.



*Palliative Care,  
Improving quality of life  
for patients and families*

## Tribute to R. David Bourke

We would like to pay tribute to our friend and colleague David Bourke who died in May of last year. David was Co-Chairman of the Council from its inception in 1994 until 2001.

As Bernard Shapiro, then Principal of McGill University, said so eloquently at his memorial service, “David Bourke was the ultimate gentleman. He was polite in a way that only deep respect for others could produce. He was clever without being arrogant, open-minded without being empty-headed. He was accomplished without being self-centered, and he was good humoured without being silly. He was infinitely caring without being mawkish or sentimental. We will all miss him from our lives.”

## Happenings!..

### Hike for Hospice

The Council will host *Hike for Hospice*, which is held in several cities across Canada. This is the first time this event will be held in Québec. It will take place on May 2nd at the Circuit Gilles Villeneuve. Registration is at 9:00 A.M. and the *Hike* will begin at 10:00 A.M.

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### Annual Sandra Goldberg Memorial Lecture

The Council sponsors this lecture annually as part of its series *Lessons In Living From The Dying*.

The next lecture will be on Tuesday, May 4, 2004 at 5:30 P.M. at the Palmer Howard Amphitheatre, McGill University. The lecturer will be Dr. David Kissane, Chairman of Psychiatry and Behavioural Sciences, Memorial Sloan-Kettering Cancer Center, New York. Dr. Kissane’s topic will be “*Discovering Meaning in Illness and Suffering*”.

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### Resource Folder

The Council has put together a Resource Folder relevant to palliative care, in the Greater Montreal area, to assist both families and caregivers to understand the issues and to help them find the necessary services. The folder has been distributed to CLSCs, the Victorian Order of Nurses (VON), hospitals and palliative care clinics and will be given, free of charge, to caregivers and families of patients who are terminally ill.

Included in the folder is a CD Rom of *Caring for Loved Ones at Home*, in both French and English. Also included on the CD and on our Web site are links to other relevant sites.

If you would like to have a Resource Folder, please contact any of these organizations or institutions or call the Council at 499-0345.

These Resource Folders are in memory of Evelyn Pearl and have been made possible by a donation from her family.

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### Humour Cart

A ‘humour cart’ is a mobile, multi-media unit with audio-

visual material with a humorous content.

Humour is widely accepted for its positive psychological and physiological effects. It helps to minimize stress by facilitating the resolution of end-of-life issues as well as by promoting the release of tension and anger. These benefits, in addition to many others, are all supported by research. They allow those who are terminally ill a greatly improved quality of life at this most challenging time. Living with a terminal illness is no easy matter; it affects not only the patients but also their loved ones and caregivers.

The Council has two Humour Carts which are loaned, for a period of six to eight months, to institutions caring for the terminally ill or chronic care patients.

If you would like to reserve a cart for your institution, please call the Council at (514) 499-0345.

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### Workshops

The Council organizes workshops at hospitals, churches, synagogues and other locations in the greater Montreal area. These workshops are offered to caregivers, health-care professionals and the general public. Some of the topics covered are: The Dying Process, Ethics in Palliative Care, Communication – What to Say When you Don’t Know What to Say, Communicating with your Physician, The Grief Journey, Hands on Care and Music Therapy.

The Second Annual **R. David Bourke Memorial** workshops will be held in October at St. Andrew’s-Dominion Douglas Church in Westmount. (date to be announced)

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### 15th International Congress on Care of the Terminally Ill—September 19-23, 2004

The Council sponsors a plenary at the International Congress on Care of the Terminally Ill, which takes place in Montreal biennially.

This year the plenary will be, “Narrative Medicine,” presented by Richard Kearney, of Newton, MA and Rita Charon of Columbia University, NY.