

Council on Palliative Care

**Palliative Care
Week 2005
May 2 to 8**

*“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
(pioneer of the modern Hospice movement)*

The McGill Cancer Nutrition-Rehabilitation Programme

By: Wilma Falconer, RN, BsN, OND

David, the great King of Israel, who ruled over 3,500 years ago, probably suffered from prostate or kidney cancer. Scholarly inquiry of ancient biblical texts, in which the king stated “I forget to eat my bread, my flesh failed of fatness and my bones cleave to my skin” indicate that he was suffering from cancer wasting, otherwise known as cachexia. (1)

Cancer cachexia ultimately affects 80% of people with advanced cancer, yet cancer-wasting remains under studied and indeed under treated. It is a complex metabolic process whose mysteries are still being unraveled. Previously, it was thought that cachexia was caused by the cancer stealing nutrients from the patient, and along with the creation of toxins, caused lack of appetite and poor food intake. Today, we know that the ‘tumour –steal’ hypothesis is wrong. Recent research suggests that products produced by the cancer and the host’s immune system, promote a release of inflammatory molecules;

these are thought to be the primary culprits giving rise to this wasting syndrome. As chaotic biochemical pathways are set in motion by this molecular “hot-pot”, the body’s efficient use of energy is disrupted and a purposeless inflammatory response prevails. Wasting is found mainly in people with solid tumours, especially advanced lung and upper gastrointestinal cancers.

As of yet, no single intervention reverses the deterioration in quality of life, dignity, and early death, often associated with cancer wasting. Dependency on others promotes costly care, with burden on families and community. Cancer is a chronic disease and the work of living with cancer entails dealing with changes in identity, body image and daily living. The hallmark of advanced cancer remains the extreme changes in body composition and appearance. Superb symptom management is possible in cancer wasting. A synergistic team approach is indicated; incorporating

nutritional counseling, ideally by dietitians in cancer care, appropriate physical therapy, tailor-made for the patient’s needs and abilities, and supervised by specialized physiotherapists. Nurses and physicians play an integral part in this team, empowering and educating patients and families, encouraging them to work in partnership with healthcare providers, and not remain just passive recipients of care. Such an approach has been developed by the MCGILL CANCER NUTRITION-REHABILITATION PROGRAMME. This unique project has been launched to combat weight and functional loss in individuals with cancer. Clinics are presently functioning both at the Montreal General and Jewish General hospitals.

Our mandate is to:

- Conduct research aimed at understanding the biological reasons why some cancer patients suffer from poor appetite, fatigue, malnutrition and loss of function.

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

Co-Chairpersons:
Richard L. Cruess
Kappy Flanders

Advisor:
Balfour M. Mount

Members:
Arlene Alter
Barbara Bishop
Sue Britton
Gretta Chambers
Linda Crelinsten
Dawn Cruchet
Teresa Dellar
Armand Des Rosiers
Joan Foster
Linda Greenberg
Lois Hollingsworth
Leslye Lang
Neil MacDonald
Michael Mikelberg
Norma Mulder
Suzanne O'Brien
Dany Pollack
Andrée Prendergast
John Sanford
Ibby Shuster
Joe Stratford
Anna Towers
Michèle Viau-Chagnon
Ellen Wallace

Secretary:
Frances Morris

Volunteerism in Palliative Care

by Rosemary Byrne

VOLUNTEERING

As citizens, we **need** to give back to our community. Communities have limited resources, and unless we give back, our communities will be depleted. The greatest resource of any community is its citizens. Citizens drive and create community in their likeness, and respond to community needs with creativity and imagination. Citizens volunteer. When we look at the history of most of Montreal's hospitals, they were founded by thoughtful, inspired community leaders, by volunteers, in fact.

But citizens need to find a way **in** to the process.

In preparation for the International Year of Volunteers, Volunteer Canada undertook a study of volunteering across our country. In their report, Volunteer Canada wrote that the reason that people cited most often for **not** volunteering is that they had never been asked. **Never been asked..** Imagine!

Volunteer managers believe that we do ask, I certainly think that I am constantly asking for volunteer support, we think that we are always recruiting and that we are always willing to accept new volunteers. But traditional broad recruitment campaigns may not be working that well. A more personalized recruitment strategy may be more effective in the long run. According to Volunteer Canada, the most effective recruiters of volunteers are volunteers themselves. So if recruitment is the issue, we might need to think about a one-on-one recruitment strategy, in which each of our volunteers is required to ask someone of their acquaintance to join our group of volunteers and then to follow-up with the contact. In other words, all of the volunteers are responsible for building

the volunteer base. When volunteers believe in an organization and support its cause, they are an effective spokesperson and can sell it in the community.

Citizens become volunteers for several reasons; the most important reason cited in the study was a strong belief in the cause, or being personally affected by the cause. People also mentioned the desire to explore new skill sets, or put new skills to use, or meet people. In palliative care, incoming volunteers are often motivated by the desire "to give back". Grateful for the quality of care their loved ones received, they offer to join the team of volunteers.

VOLUNTEERS IN PALLIATIVE CARE

Volunteers are essential and fundamental to quality palliative care. Volunteers enhance, complement and support the care provided by the inter-disciplinary team. They humanize the patients' care: by offering a smile, by serving a cup of tea, by massaging hands, by fluffing pillows, by adjusting blinds, by reading to patients who can no longer do so for themselves, by wheeling the patients out for a change of air, by simply having time for the little things. Volunteers are good neighbours, who do not have an agenda when they enter the patients' room. It is a patient-directed relationship. Volunteers are there to listen, or sit with the patient in complete silence. Volunteers offer respite to families who are unwilling to leave their loved ones unattended. Sometimes, they are the only visitor the patient sees in the course of a week. In palliative care, volunteers have the luxury of simply **being**.

BECOMING A VOLUNTEER

In order to become a volunteer in palliative care within the network of the McGill teaching hospitals, volunteers

Continued on Page 3

Volunteerism in Palliative Care *(Continued from page 2)*

must complete 18 hours of training. Each spring and fall, the McGill teaching hospitals organize training sessions for incoming potential volunteers. The hospitals take turns hosting the training session. This spring's session will be held at St Mary's Hospital. In order to enrol in the training program, potential volunteers can register by contacting the palliative care volunteer managers at the Montreal General Hospital, the Jewish General Hospital or St. Mary's Hospital. There is a registration fee of \$35.00 which covers photocopies and light refreshments.

The training session is divided into modules which are presented by experts in the field. Topics include: the role of the volunteer, the philosophy of palliative care and the team approach, the dying process, how to speak to the patient and their family, the many faces of palliative care, grief and loss, ethnic and cultural diversity, ethics for volunteers, supporting families, and boundary issues and self-care.

After completion of the training session, the volunteers can apply to one of the hospitals. The palliative care volunteer managers from the McGill teaching hospitals are present for the training session, and distribute application forms to potential volunteers. Volunteering in palliative care is very rewarding, but it is not for everyone. So screening is an important part of the process, as the goal is to match the volunteer to the program. Volunteers may want to visit several of the McGill sites before choosing their hospital, and the hospitals as well choose their volunteers. The volunteers are interviewed and, if accepted, are given an orientation to the service. Most programs have new volunteers "shadow" experienced volunteers for the first month or two.

If you are interested in working as a volunteer in palliative care, the time is right, as a new course is beginning in early May.

**Rosemary Byrne, Palliative Care Volunteer Services Manager
Hope and Cope, Jewish General Hospital**



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

Cancer Nutrition-Rehabilitation Programme

(Continued from page 1)

- Offer nutritional and rehabilitation programmes for patients who are suffering from these symptoms.
- Educate patients, family caregivers and other health professionals in new ways to manage the above symptoms.

Cancer cachexia is as much a social and cultural phenomenon as it is a biological. More exploratory studies into the lived experience of both people suffering from cachexia and their loved ones, watching the person wasting away, are warranted for a greater understanding. A new vision of care for people with cancer wasting is to enable those people with advancing cancer, to maintain dignity, function, and rekindle a sense of hope for the future. Just like the opening of Pandora's box, where hope flutters out, following the flood of miseries, to offer consolation, compassion and care.

The McGill Cancer Nutrition-Rehabilitation Programme's (CNRP) web site is: www.mcgill.ca/cnr.

Wilma Falconer, Clinical Research Nurse Coordinator (CNRP)

¹The Disease That Caused Weight Loss in King David the Great Liubov (Louba) Ben-Noun. *The Journals Of Gerontology: Series A* : Biological sciences and medical Sciences. Washington: Feb 2004. Vol. 59A, Iss. 2, p. 143-145 (3 pp.)

Happenings!..

A Corner for the Children

During the past few years we have seen an increase in the number of children coming to visit relatives on the palliative care units in our McGill affiliated institutions. Parents seem more willing to bring children to visit and the staff is more open to having them there. It is particularly important that children are kept informed and given the opportunity to say goodbye. In her book, *When a Parent is Sick: Helping Parents Explain Serious Illness to Children*, Joan Hamilton states, "Children will have a smoother adjustment to change if they feel they are included – if they know, to their level of understanding, what is going on. Children then have the opportunity to work at, and work through, their feelings at the same time as everyone else."

There is a need to have, in the Family Room on each of the Units, if possible, a corner for the children, a place where they can sit and read, draw, make a puzzle or play a game. Some of the staff has suggested that each child should receive a "distraction bag" – a bag that contains a small stuffed animal and a travel size game. These can be given to all of the children who come to visit. We are excited to be working with *Oink Oink* who will help us to put these bags together.

The nurses and volunteer coordinators were pleased to learn that the Council is interested in raising funds to provide these games, books and puzzles for these young visitors who come to the Jewish General Hospital, Montreal General Hospital, Mount Sinai Hospital, St. Mary's Hospital and the West Island Residence.

In addition to the supplies for the Children's Corners, another need was identified by the palliative care teams. Parents have been asking staff what to tell their children prior to their coming to visit and how to answer their questions afterwards. Many of the staff have never worked closely with children facing these difficult situations. Parents have rarely dealt with the topics of serious illness and death with their children. There is an urgent need for readily accessible resource material for both parents and staff to help them inform and support the children during this very difficult time. The Council will also raise funds to purchase books and other resource material for parents and staff to help children understand illness, loss and grief.

Hike for Hospice

The Council will host the *Hike for Hospice Palliative Care*, which is held in many cities across Canada annually. This is the second year that this event will be held in Québec. It will take place on May 1st at the Parc Jean-Drapeau, Circuit Gilles-Villeneuve. Registration is at 9:00 A.M. and the *Hike* will begin at 10:00 A.M.

Last year's Hike was fun in spite of the rain! There were approximately 100 'Hikers' and the event raised just under \$15,000.



Hike for Hospice 2004 — the weather might have been damp, but our spirits weren't!!

Proceeds from this year's Hike will be divided between The Council (for the Children's Corners) and The Lighthouse, Children and Families to build and operate Québec's first respite home and pediatric palliative care facility.

Workshops

The second annual **R. David Bourke Memorial** was held on October 19th, 2004 at St. Andrew's – Dominion Douglas Church. The topic was *End-of-Life Decisions - Yours to Make*. The panel discussion was moderated by Richard L. Cruess, M.D. Co-Chairperson of The Council on Palliative Care. The panellists were Michael Dworkind, M.D., Associate Professor of Family Medicine, McGill University; Carolyn Ells, Ph.D., of the Biomedical Ethics Unit, McGill University; and Peter Goldberg, M.D., Intensive Care Physician at the MUHC, Royal Victoria Hospital. All who attended found the discussion very informative, interesting and educational.

Three workshops were held at St. Mary's Hospital in November 2004. Joan Foster, a CLSC homecare nurse, spoke on *Coping with the Challenges of Caregiving*.

Happenings!..(cont.)

Dawn Cruchet, a grief educator, talked on *The Power of Grief* and Suzanne O'Brien, the Program Director of Hope and Cope at the Jewish General Hospital, covered, *Communication in Palliative Care*.

The Unitarian Church of Montreal hosted three workshops in February and March 2005. Sue Britton, a psychotherapist, spoke on *An Overview of Palliative Care*, Joan Foster on *Home vs. Hospital: Exploring the Options* and Suzanne O'Brien presented *Communication in Palliative Care*.

All of our projects depend on the participation of the speakers who volunteer their time. The Council is extremely grateful for their help and ongoing support.

Further information about the workshops can be found on our web site.

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 3, 2005 at 5:30 P.M. at the Palmer Howard Amphitheatre, McGill University. The lecturer will be Dr. Diane Meier, Director of the Center to Advance Palliative Care and Professor of Geriatrics and Medicine at Mount Sinai School of Medicine in New York. Dr. Meier's topic will be "*Palliative Care In Hospitals*".

15th International Congress on Care of the Terminally Ill

The 2004 Congress was very successful, attracting 1257 participants, from 34 countries. The scientific program, the concert and the public evening contributed to making this a very special event.

The Scientific Program included six concurrent all-day seminars, seven plenaries, three hour-long research fora and 84 workshops. Sixty-five invited speakers were joined by 178 presenters of research papers, proffered workshops and posters. Clinical topics, psychosocial issues and volunteers' concerns were covered during the sessions.

The Council on Palliative Care sponsored the plenary titled 'Narrative Medicine', presented by Professor Richard Kearney and Dr. Rita Charon. This plenary looked at how narrative may relieve pain through a therapeutic practice of empathy, catharsis, working-through and pardon. The speakers drew on examples from philosophy, anthropology and psychotherapy.

The Concert at St. Patrick's Basilica was enjoyed by

over 1400 people. It was the first scheduled concert of the season for Les Violons du Roy and La Chapelle du Québec. Maestro Trevor Pinnock and four highly regarded soloists provided a memorable concert, which was broadcast live by CBC (Radio2).

This year's Public Evening was the premier of the documentary, *The Man Who Learned to Fall: Lessons from the Edge of Being*. This film documents the life of Philip Simmons, a gifted writer and teacher, who celebrates life as he is slowly dying of ALS.

The 15th International Congress on Care of the Terminally Ill provided the opportunity for shared learning and networking.

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 in understanding the issues and to help them find the necessary services. The **Resource Folder** is available, free of charge.

Included in the folder is a CD ROM, *Caring for Loved Ones at Home*, in both French and English, *What To Do In The Event of Death*, a publication from the Québec government and links to other relevant web sites.

If you would like a Folder, please contact the Council.

The Resource Folders are in memory of Evelyn Pearl and have been made possible by a donation from her family. The Council is extremely grateful for their generosity.

Congratulations!

To the Council's Bowling Team who took home the first place trophy for the second consecutive year!

Each May, during Palliative Care Week, Palliative Care McGill organizes a bowling tournament. It is a time when the people who work in palliative care in the MUHC can meet each other for mostly fun and some 'friendly' competition.



From l to r: Lois Hollingsworth, Heidi Yane, Sue Britton, Joan Foster, Frances Morris, Ellen Wallace