HOT SPOT

The Newsletter of the Rapid Response Radiotherapy Program
of the Odette Cancer Centre

Sunnybrook
ODETTE CANCER CENTRE
A Cancer Care Ontario Partner

Volume 9, Issue 4, November 2007

Editorial

By May Tsao, MD, FRCP(C)

The Rapid Response Radiotherapy Program (RRRP) at the Odette Cancer Centre is pleased to welcome Dr. Arjun Sahgal (Radiation Oncologist). Dr. Sahgal recently completed a Fellowship at the University of California, San Francisco, and has interest in spine metastases radiotherapy. We look forward to Dr. Sahgal's contributions to the RRRP site group.

In this exciting and interesting edition of **Hot Spot,** our contributors provide insight into many issues facing our palliative patients.

Two of these topics are pertinent to children such as Lysa Toye's article on "What hope can mask: Talking to children about life-threatening illness", or Camilla Gryski's article on "The role of the therapeutic clown in the care of children with progressive life-limiting conditions".

Julie Napolskikh, Dr. Jeff Myers and Dr. Debbie Selby explore palliative care unit length of stay and palliative care unit attributes considered meaningful by health care professionals.

We have two inserts in this issue titled: "Update in the management of colorectal cancer" by Dr. Yoo-Joung Ko, and "The evolving role of cannabinoids in supportive oncology" by Dr. Vincent Maida.

We hope you enjoy reading not only these articles, but also the other articles highlighted in this edition of **Hot Spot.**

What hope can mask: Talking to children about life-threatening illness and death

By Lysa Toye, MSW, RSW, Dip EXAT

For adults receiving a diagnosis of life-threatening illness, it appears a natural survival strategy to focus their energy, thoughts and attention on the hope of recovery or cure, leaving the fear of the alternative, advancing illness and death, to lurk in the shadows. With time and deeper probing, however, we often recognize that this hope for many people is more than a simple expression of the longing, tenderhearted embrace of life. All too often in our culture where the infirm body is a battleground, hope works like a sword – and sometimes like a life vest – to defend dying people against their dying. Families focusing on their hopes for their loved one's recovery will often paint an exclusively hope-driven picture for children when telling them about their illness. This leads to the situation that we see so often as health care professionals where an adult has been sick for some time and is now imminently dying, and no one has spoken to the children about death or prepared them for what is going to happen.

This is true of a client I met recently who has lived with cancer for many years through numerous periods of acute illness and restabilization. Although she had outlived a number of short-term prognoses, she had never discussed the possibility of her dying with her adolescent children. When she was referred by her palliative care physician to the Max and Beatrice Wolfe Centre for Children's Grief and Palliative Care, she and I had a number of discussions wherein she reiterated her belief that it was better not to talk about dying because her faith encouraged her to "stay positive" and pursue positive thoughts. While, undoubtedly, this determined hope was meant to protect both herself

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In this issue of HOT SPOT:

The role of experience and meaning in clinical ethics

Karen Faith, BSW, MEd, MSc, RSW, Director Clinical Ethics Centre

T.S. Elliot once wrote, “We had the experience, but missed the meaning”. In clinical ethics consultation, we often confront very complex patient situations in which each person involved has a unique experience and often a different interpretation or “meaning”. The challenge in most health care settings is ensuring that there are sufficient opportunities to reflect on important experiences and their meaning.

Mrs. J* was very concerned about her mother, a patient receiving treatment that included surgery for heart problems. Mrs. J would ask the nurse looking after her mother dozens of questions, many of which had to be addressed by the attending physician. Because of rotating responsibilities, the attending physician would often change. Some members of the team experienced Mrs. J as a “high-maintenance” family member. Other members of the team saw Mrs. J as caring and involved in her mother’s health. Mrs. J experienced certain staff as distracted, too busy to be interested in addressing family members while other staff she found supportive because they included her in the care of her mother. Although all of the staff who looked after Mrs. J’s mother experienced the same repeated questioning, several had missed the real meaning of Mrs. J’s actions – the fear that she would miss addressing something very important and, ultimately, lose her mother. During the consultation on this case, it was discovered that Mrs. J’s father had died from an avoidable complication while in hospital only a few years earlier.

Experience and meaning are key considerations in ethics consultation. When consulting with health care teams, clinical ethicists often encourage team members to examine the difficulties faced while reflecting on important ethical obligations concerning patient care. This process of reflection includes helping the team to describe their experiences in providing care, as well as considering the experiences of patient and family. While supporting team members to reflect on the “meaning” of these experiences, we ask them to consider important ethical obligations as well as their professional ideals. The team members who cared for the patient understood that Mrs. J’s need for information arose from a previously difficult experience around communication within another health care setting. In a spirit of negotiation, the team set up regular phone calls with the attending physician and invited Mrs. J to write her comments and questions to be shared with the physician prior to these calls. Within days of instituting this new approach to communication, Mrs. J seemed less anxious and developed a more comfortable relationship with her mother’s care team.

Key to maintaining high ethical standards for patient care and for professionalism is this process of reflection. It includes examining experience and meaning as they pertain to the daily ethical challenges and obligations faced by health care professionals. To support ethics in daily practice, the Clinical Ethics Centre has developed an Ethics Pocket Tool. This two-sided laminated card contains ethical considerations as well as relevant questions designed to help teams to reflect on ethics in the daily practice environment. For more information or to request a copy of the Ethics Pocket Tool, please contact Jason Marshall at extension 4818.

* *This is not an actual case, but is based on aspects of different patient care scenarios that were actual clinical ethics case consultations.*

What hope can mask

…continued from page 1

and her children from the anguish of contemplating her death, its unfortunate effect was that her children were unable to openly ask questions about what might happen or explore the fears, sadness, and anger they felt for their mother and for themselves. It is always difficult to decide when to introduce the possibility of a loved one’s death to a child or young person, but we often leave it far too late. Ideally, when we talk to children and youth early and openly about the full range of possible outcomes of a family member’s life-threatening illness, we can create a supportive environment that will hold the evolving range of their hopes, fears, and wonderings over time, helping them to learn to live with what is happening in their world.

I was interested in my client’s belief that opening up discussion with her children about the possibility, indeed, the likelihood that she will die from her cancer, might take away their hope. It may be, rather, that opening herself up further to this possibility would damage the small hard-won security she derived from her faith, and I wondered about this prevailing, but covert view, of hope and realism as opposites. While hope is usually understood to be the force that enables us to live with a serious diagnosis, it could also be argued that it does exactly the opposite, separating us from the reality of life-threatening illness and, in some cases, of dying. It is the natural impulse to protect children so that they will “be alright” that leads parents to not tell them what is happening. What is truly required for children and youth to weather the storm of parental illness or death, however, is honesty, openness, time and a place for their feelings to be tended. This requires us, as health care professionals, to walk with the families we serve into the darkness of what we do not know about advancing illness and dying, what we fear most about loss of control. It challenges us to walk into the storm of suffering, recognizing heartbreak, our own, our clients’, and their children’s, as part of the natural course of living and dying.

Although relatively little has been written in the developmental literature about maturational tasks of adulthood, some authors and traditions recognize as a deep developmental task the capacity to tolerate uncertainty, ambiguity, and the unknown. Certainly this is not universally achieved in today’s culture, which has an ever-growing thirst for control and mastery over our environments. But

The role of the therapeutic clown in the care of children with progressive life-limiting conditions

By Camilla Gryski, MLS, MEd

The clown may be an unexpected presence in the health care setting, but historically and culturally, from medieval jesters to the sacred clowns of many First Nations peoples, clowns have been associated with healing and the well-being of society.

Today's therapeutic clowns are members of the health care team, often closely associated with child life departments. Therapeutic clowns wear minimal make-up, and are sensitive to the reactions of patients, their families and the staff, as well as to the requirements of the hospital or home environment. In 2005, concerned about the proliferation of clowns in hospitals, therapeutic clowns working in Canada formed The Canadian Association of Therapeutic Clowns/L'Association Canadienne des clowns thérapeutiques. Each member agrees to abide by the organization's Statement of Principles and Code of Ethics.

Clown historian John Towsen suggests that the clown's ability to evoke feelings of superiority in the spectator plays a hidden role in all clowning. The therapeutic clown works to empower children, offering choices and encouraging a sense of mastery at a time when there may be many limitations in their lives. The clown's frequent inability to manage ordinary aspects of everyday life gives rise to gentle humour, and the child has the much-needed opportunity to give as well as receive care.

Anthony Hippisley Coxe, comments on the relationship between clowns and children: "Children love him for a simpler reason. He expresses loudly and eloquently the bewilderment they feel when they find themselves in an adult world".

The red nose of the clown deprives its wearer of all other masks. The vulnerability of the clown engages the child and helps to build a supportive relationship. The clown is perceived as being out-of-place in the health care setting, as is the child, and in this way they can become allies. Barbara Sourkes suggests that the establishment of "a secure therapeutic alliance" is an intervention in itself.

The incongruity that results when a clown walks down a hospital hallway or, indeed, into a living room, is a source of both amusement and expectation. When a clown asks permission, then steps across the threshold into a room, almost anything can happen. Her presence is an invitation to both the child and family to come out and play.

When we consider the needs of the child with a progressive life-limiting illness and look towards holistic care, play is also of paramount importance. As one of the rights of the child and as a natural activity of childhood, play offers opportunities for normalizing a situation that is extraordinary.

Children will often ask for a visit from their therapeutic clown – who very graphically represents playfulness – until just a few days before their death. As Joanne Hilden and Daniel Tobin point out, dying children have a natural tendency to live in the present and an ability to cherish play and other pleasant experiences.

Sourkes comments on the life-threatened child's particular need for safety: "In a sea of uncertainty, the child's ongoing quest is to find a 'safe place' within the storm". Together, children and therapeutic clowns create safe and comforting play worlds, full of imagination and story. A bubble is suddenly food for a hungry puppet. A child requests a favourite rainbow face-paint tattoo time and time again. A game of Hide and Seek, when the child sets the rules, becomes an exploration of absence, missing, and joyful reunion.

The clown has been called "life-enhancing". The therapeutic clown works to enhance the quality of life for children with life-limiting progressive illnesses and their families. Moments of play, gentle humour and just plain fun shared with a trusted clown companion can help to relieve a child's symptoms of distress and contribute to psychosocial care. For the child and the family, therapeutic clown visits offer a time away from the concerns of illness, and help to create lasting memories.

About the author

Camilla Gryski is currently contracted by the Palliative and Bereavement Care Service at Sick Kids to offer specialized therapeutic clown services to children with life-limiting illnesses and/or their families.

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children, perhaps even more than adults, have a remarkable capacity to hold two or more contradictory alternatives alongside one another. They are capable of understanding, with loving support and sensitive ongoing dialogue, that a parent with cancer may or may not die from their disease, and of holding both passionate hope and uncertain, realistic information openly in their two hands. Further, they can benefit from being included early on as an important member in family discussions and decisions about what is happening in the ill person's care and treatment. This can solidify their sense of position and security in the family and activate their engagement with their loved one through the course of the illness, creating opportunities for meaningful presence and contribution through expressions of love or taking on of concrete tasks. Sharing the family's emerging understanding of a life-threatening illness with children and youth well before the 11th hour gives them time and opportunity to explore, express and learn to carry their feelings. In the case of a temporary or long-term return of health, children and youth can better understand the gift of the time they are given. In the case where death is the eventual outcome, it opens the opportunity to children and youth to use the time available to them with a loved one to share and prepare, individually and as a family, finding their way to the heart of their situation and preparing for the change in everyone's life. In any eventuality, children and youth are invited to grow into that most subtle wisdom: to recognize the preciousness of life, moment to moment, and to live in the heartbreaking fullness of what it presents to each of us.

Provincial integration project moving forward at Odette Cancer Centre

By Martha Wyatt, MHSc – Health Admin, CHE, BScPT, BScH

In February 2007, Dr. Deb Dudgeon introduced the Provincial Palliative Care Integration Project (PPCIP) to Hot Spot readers; a provincial improvement initiative supported by Cancer Care Ontario aimed at improving symptom screening, assessment and control and coordinated palliative support. In the Toronto Central LHIN, Odette, along with Princess Margaret Hospital, Toronto Central CCAC, St. Michael's Hospital, Humber River Regional Hospital and Dorothy Ley Hospice, embarked on this initiative one year ago September.

At Odette Regional Cancer Centre, the standardized assessment and care management tools of the PPCIP, including Edmonton Symptom Assessment System (ESAS)[*], Palliative Performance Scale (PPS)[†] and Symptom Management Guidelines (SMG)[‡] have been implemented in the initial target populations of lung and palliative care clinic patients. The next step is the integration of collaborative care plans. These tools are targeted to improve communication and consistency of care for cancer patients. The most recent group to embrace these tools at Odette has been the Rapid Response Radiation Program (RRRP) and just emerging is the gynecology group.

The PPCIP is an improvement project and, as such, encourages each area to implement the tools in a way that makes sense for their population and their workflow. With this in mind, the RRRP program designed their flow (Diagram One). When a patient arrives for treatment they are asked to complete ESAS at a touch screen kiosk. After the symptoms have been rated, a histogram[§] is printed of their symptoms over time. ESAS as a screening tool not only allows for quick identification of symptoms to be further assessed that day, the histogram also allows for trending of symptoms improving clinicians' understanding of a patient's experience. Because the RRRP program does not normally follow up with patients, the team discussed the need to convey the information gained by ESAS to referring physicians. The histogram is now being faxed along with the normal note to the referring physician and any scores that are identified as problematic are noted.

The other score recorded and faxed is the PPS. This scale not only identifies decline over time, it also coincides with CCPs. A score between 40 and 60 is the transitional period between stable and end-of-life stages and is an important time to recognize the need for increasing supports and possibly services. Toronto Central CCAC is using this score to better identify by functional status and evidence of disease those patients who would benefit from palliative services in the community, an exciting opportunity.

If you are interested in more information or would like to order these tools for your use, please go to **www.cancercare.on.ca** to information and services and choose Provincial Palliative Care Integration Project.

Alternatively you may contact:

Martha Wyatt, Regional Improvement Coordinator for Toronto Central LHIN, **martha.wyatt@uhn.on.ca**

Dr. Lesia Wynnychuk, Palliative Physician Lead, **Lesia.Wynnychuk@sunnybrook.ca**

Pat Daines, Clinical Nurse Specialist and Professional Practice Lead for Palliative Care, **Pat.Daines@sunnybrook.ca**

Emily Sinclair, RRRP Therapist, **Emily.Sinclair@sunnybrook.ca**

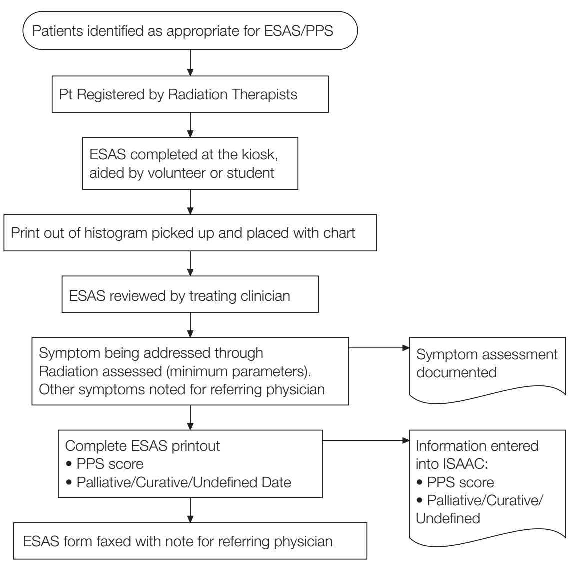

Diagram One: RRRP clinic flow

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[*] Self-assessment tool asking patients to rate nine symptoms between 0-10 (nine most common symptoms experienced by cancer patients). Zero is the absence of a symptom and "10" is the symptom is at its worst.

[†] Assesses key determinants of patients' physical status, evidence of disease and functional performance. Rated in increments of 10 from 0-100. Identifies decline over time and is sensitive to change at the lower end of the scale (0-30).

[‡] Resource for physicians and advanced practice nurses in the treatment of symptoms commonly experienced by palliative care patients. Pocket and PDA versions available for easy reference.

[§] Histograms are printed from the CCO database, "ISAAC", implemented in five RCCs and each of their CCAC counterparts in Ontario with further implementation across the province planned to start this fall.

Update

As of August 10, 2007, the Australian Therapeutics Goods Administration (TGA is the Australian equivalent of Health Canada) had received eight reports of serious liver adverse reactions associated with use of Lumiracoxib, including two deaths and two patients requiring liver transplants. All these reports have been received since March 2007, with six reports received in the last six weeks before August 10, 2007. The doses of Lumiracoxib involved appear to be 200 mg or 400 mg daily whereas the maximum recommended dose in Canada is 100 mg OD. The Australian TGA has urgently investigated these reports and, as a result, has acted to take the drug off the market in Australia. Health Canada is reviewing the use of Lumiracoxib in Canada. **http://www.tga.health.gov.au/alerts/prexige.htm**

Sol Stern, BSc, MSc, MD, MCFP
Chair of Palliative Care,
Halton Healthcare Services
Past-President of the
Ontario Palliative Care Association

New research in palliative care

By Shannon Ellis, MA, PhD, Student in Applied Social Psychology at the University of Guelph, Linda Wood, PhD, Professor in the Psychology Department at the University of Guelph, and Dr. Lorraine Wood, Home Palliative Care Physician with TLCPC

Shannon Ellis and Linda Wood (Applied Social Psychology, University of Guelph) together with Lorraine Wood (physician at Temmy Latner Centre of Palliative care) are developing a program of research to look at the ways in which physicians, patients and family members interact in home palliative care settings. The approach that will be used is Conversation Analysis (CA). CA is a form of qualitative microanalysis that involves looking repeatedly at videotapes of interaction with the aid of a detailed transcript. The aim is to identify the various actions and activities that are accomplished through the use of talk and other features of interaction. Through examination of the fine details of interaction (e.g., overlapping speech, hesitation, repetition, silences, audible exhalations, intonation, momentary touches, idioms), this approach can identify the specific ways in which physicians, patients and families manage the challenges of palliative care. For example, it allows researchers to show precisely how pauses in speech work to convey agreement or disagreement and how stepwise questioning can work to solicit or display the patient's perspective on his or her future.

Some of the questions that can be addressed using this approach are: How do physicians and patients talk about death and dying without necessarily using those words? How do physicians convey to patients and families the news that the cancer is no longer treatable, that the patient is close to dying and that the focus of treatment is shifting from cure to managing pain? How can decision-making be done in a collaborative way among physicians, patients and family members? How do people resolve problems such as when to call the doctor or the ambulance? How do physicians manage the delicate matter of giving enough, but not too much information, or of offering advice? How do interactions among physicians, patients and family members change within a visit and over a period of time? How are the stories told by patients and families used to convey feelings and identities? How can physicians, patients and families work together to accomplish shared understanding?

This approach is very different from that used in research that uses interviews or questionnaires administered after visits have taken place to assess patients' and families' views of the quality of care and their satisfaction with care. Although there has been a good deal of CA work on medical interactions, CA has not been applied systematically to interactions in home palliative care settings. The aim of this new research is to understand how the actions and activities of physicians, patients and families are carried out in real time in the specific social, communicative and physical context of home palliative care. The ultimate goal is to identify precisely how the work of providing care gets done and to provide suggestions that can improve the practice of home palliative care.

Health care professionals' perception of what defines "meaningful palliative care" in a palliative care unit

By Julie Napolskikh, BSc(C), Jeff Myers, MD, CCFP, MSEd, and Debbie Selby, MD, FRCPC

In the context of end-of-life, palliative care focuses on providing holistic care to help maximize patient quality of life and attempt to fulfill their idea of a "good death". In addition to care at home, inpatient palliative care units (PCUs) offer comprehensive multidisciplinary care with teams of physicians, nurses, social workers, clergy, therapists, and trained volunteers. Currently, little Canadian data exist addressing certain elements of care in PCUs. We examined length of stay (LOS) and PCU attributes considered meaningful by health care professionals.

Nurses, physicians, social workers, and allied professionals from oncology, internal medicine (GIM), and palliative care (PC) were approached with our exploratory open-ended questionnaire to identify minimal, optimal, and excessive LOS for a meaningful PCU stay and to define "meaningful" in this context. The study took place at Sunnybrook Health Sciences Centre (SHSC) in Toronto, Ontario, which houses a 24-bed PCU, and at a nearby PCU in Baycrest Geriatric Hospital.

One hundred and three surveys (71% response rate) were returned: 31 physicians, 44 nurses, 20 social workers, and eight other allied professionals. Fifty-six respondents were from oncology departments, 14 from GIM, and 33 from PC. The median LOS for minimum, optimal, and excessive was 7, 28, and 90 days, respectively. Interestingly, 25% of respondents identified even a one- to two-day stay in the PCU as potentially meaningful. This coincides with studies suggesting that any LOS is beneficial, although lower family satisfaction has been reported to be associated with shorter LOS. There was a wide range in responses but, overall, group replies in our study were similar – a finding relevant for patient care as it implies similar expectations between the referring staff and the receiving PCU staff. The only significant differences ($p<0.01$) occurred between **minimum** LOS medians (days): (i) social workers = 3 versus nurses = 14, (ii) oncology = 7 versus PC = 3 and GIM = 2.

Seven themes emerged from the "definition of a meaningful stay" question, the most prevalent of which were symptom control, holistic care, individual focus, and attention to family. The former three themes are in keeping with existing literature. However, attention to family, an area considered highly important by HCPs, patients, and families in an earlier study, was emphasized more by our respondents than it was in previous research. Additionally, another three less-prominent themes surfaced: preparation for death and relationship with PCU staff, which were also previously reported, and the physical environment, an area less clearly emphasized in literature. Again there was overall similarity in responses by professions and disciplines, with the only significant differences occurring between (i) physicians mentioning symptom control more often than nurses ($p=0.002$), and (ii) nurses identifying the need for individual focus more frequently than physicians ($p=0.02$).

In order to continue inquiry into Canadian PCUs, areas for future investigation include seeking opinions of HCPs in non-tertiary PCUs and those of patients and families.

Continuing Medical Education 2007–2008

By Ewa Szumacher, MD, MEd, FRCP(C)

Continuing Medical Education (CME) can update health care professionals on the latest advances for modifications to their clinical practice. At the request of the CME organizers, Hot Spot lists the national and international CME activities in palliative medicine that are of interest to our readers. Please kindly forward details of the CME activities to: **Ewa.Szumacher@sunnybrook.ca**

- December 11-13, 2007 – **14th Annual Symposium on Complementary Health Care,** University of Exeter, United Kingdom, Tel: +44 (0) 1392-424872, **camexeter@pms.ac.uk**, **www.pms.ac.uk/compmed/symposium/**
- February 5-6, 2008 – **Second International Workshop on Community Participation in Palliative Care,** Manjeri, Malappuram, Kerala, India, **pain@vsnl.com**
- February 8-10, 2008 – **XVth International Conference of the Indian Association of Palliative Care,** Chennai, India, **kochipallcon@rediffmail.com**
- April 16-18, 2008 – **2008 National Case Management Conference – The Power of Case Management,** Toronto, Ontario, **www.ncmn.ca/program_events.html**
- April 29-May 1, 2008 – **The 7th Palliative Care Congress,** The Palliative Care Research Society, The RCN Palliative Care Nursing Group and The Association for Palliative Medicine of Great Britain and Ireland, Glasgow, United Kingdom, **www.pccongress.org.uk**
- May 2-4, 2008 – **Catholic Health Association of Canada's 2008 Annual Convention 400 Years: Full of Spirit - Full of Life,** Quebec City, Quebec, Tel: (613) 731-7148 ext: 257, **www.chac.ca, sdeliencourt@chac.ca**
- May 8-9, 2008 – **Providence Health Care Conference Spirituality: The Invisible Ingredient in Health & Healing,** Vancouver, British Colombia, Tel: (604) 806-8528, **psihota@providencehealth.bc.ca**
- May 28-31, 2008 – **5th Research Forum of the European Association for Palliative Care (EAPC),** Trondheim, Norway, **www.eapcnet.org/congresses/Research2008.html**
- August 17-22, 2008 – **12th World Congress on Pain,** The International Association for the Study of Pain, Glasgow, United Kingdom, **www.iasp-pain.org/2008Congress.html**
- October 26-29, 2008 – **2008 Canadian Hospice Palliative Care Conference,** Charlottetown, Prince Edward Island, **www.chpca.net**

Continuing Medical Education Activities

- University of Western Ontario Certificate in Palliative Care and Death Studies (on-line) Service Provision in Hospice/Palliative Care, **www.advancedprofessionaleducation.com**
- Hospice Palliative Care Multidiscipline Certificate – Humber College, **pamela.mckintuck@humber.ca**
- Temmy Latner Centre for Palliative Care – Mount Sinai Hospital, **www.tlcpc.org**
- RTS Perinatal Bereavement Support Training, **www.pbso.ca**
- Comprehensive Bereavement Skills Training – COPING Centre – Cambridge, **www.griefsupport.cc**
- Humber College Annual Conference on Palliative Care – Toronto, **www.palliativecare.humber.on.ca**
- Ian Anderson Continuing Education in End of Life Care – Toronto, **www.cme.utoronto.ca/endoflife/**
- Bereavement Ontario Network Conference (each September), **www.bereavementnetwork.ca**
- National Conference of Hospice Palliative Care – Canada, **www.chpca.net**
- Palliative Care Certificate Program, Distance Program – Grant MacEwan College, Edmonton, **www.macewan.ca/palliative**
- Compassionate care for the Terminally Ill (four non-credit distance program) – Grant MacEwan College, Edmonton, **www.macewan.ca/palliative**

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Founders: Dr. L. Andersson, Dr. C. Danjoux
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Odette Cancer Centre,
Sunnybrook Health Sciences Centre,
2075 Bayview Avenue,
Toronto, Ontario M4N 3M5
Tel: 416-480-4998, Fax: 416-480-6002
E-mail: **edward.chow@sunnybrook.ca**
Website: **http://www.sunnybrook.ca/programs/occ/treatmentprevention/rapidresponse**

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