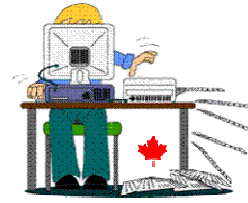


## Media Watch...

is distributed weekly to my colleagues who are active or have a special interest in **hospice, palliative care** and **end-of-life issues** – to help keep them abreast of current, emerging and related issues, and to also inform discussion and to encourage further inquiry.

## 7 June Edition | Issue #152



Compilation of Media Watch 2008, 2009, 2010 ©

Compiled & Annotated by Barry R. Ashpole

End-of-life issues: Scroll down to [Specialist Publications](#) and 'It is time for our generation to act courageously' (p.5) for an OpEd published in *Association for Death Education & Counseling*.

## Canada

### Issues in home and long term care

#### **Inefficiency squandering health resources: Report**

ONTARIO | *Globe & Mail* – 3 June 2010 – Almost half of Ontario patients who require urgent cancer operations don't get them within the recommended two weeks or less. One quarter of nursing home residents don't need to be in long-term care, while many of those who do spend months waiting to get in (see sidebar). A new report of the Ontario Health Quality Council suggests one of the most costly health care systems in Canada – consuming 46 cents of every program spending dollar – is squandering precious resources due to inefficiency.<sup>1</sup> Although quality council chairwoman Lyn McLeod stressed the report was to encourage hospitals to do better, even she noted: "In many areas of care, too many people wait too long." Chief among her concerns is that one in every six hospital beds is occupied by patients who are awaiting nursing home placement. That causes a domino effect: Many urgent cancer patients cannot undergo operations when needed due to lack of beds, and emergency patients wait for hours to be moved to a room.

<http://www.theglobeandmail.com/news/national/inefficiency-squandering-health-resources-report/article1591785/>

1. *QUALITY MONITOR*, Ontario Health Quality Council, Report on Ontario's Health System, 2010.  
[http://www.ohqc.ca/pdfs/2010\\_report\\_-\\_english.pdf](http://www.ohqc.ca/pdfs/2010_report_-_english.pdf)

#### **Lack of long-term care worse in eastern Ontario**

ONTARIO | CBC News – 4 June 2010 – The doctor responsible for health care in eastern Ontario says the region lags behind the rest of the province in providing long-term care to patients because of a lack of affordable home-care options. "We probably have 250 folks today who are in our acute-care hospitals who shouldn't be there," said Dr. Robert Cushman, CEO of the Champlain Local Health Integration Network. "Their treatment is finished. Unfortunately, they can't go home. Well, one of the reasons they can't go home is we don't have the supports to improve home-care services. [So], the apparent option is long-term care." Cushman's remarks come ... after the Ontario Health Quality Council, an arm's length agency, released its fifth annual report on wait times for health services in the province.  
<http://www.cbc.ca/canada/ottawa/story/2010/06/04/ott-long-term-care-wait.html>

## Challenges coming for end-of-life care

### **Province preparing for spike in deaths**

NOVA SCOTIA | *Herald-Chronicle* (Halifax) – 2 June 2010 – It's not a cheery thought, but a lot more people will die in the next 20 years than ever before. As baby boomers hit their 70s and 80s, the mortality rate from chronic diseases such as cancer and heart disease will spike. By 2030, the national death toll is expected to reach 500,000, according to Dr. Fred Burge of Dalhousie University. That compares to the current number of about 300,000. Our health system must come to grips with this coming wave of death and disease, said Burge, director of Dalhousie medical school's family medicine research unit. "I think we're getting there but we've got a lot of work to do," he said. "There really are big issues. If you look at the challenges of the hospital system looking after dying people, we don't have the beds and space." Burge leads a Dalhousie research project looking into what kind of

end-of-life care Nova Scotians receive, and how this care can be improved.

<http://thechronicleherald.ca/NovaScotia/1185307.html>

### **Specialist Publications**

Of particular interest:

**'Tracking the evolution of hospice palliative care in Canada.'** Scroll down to p.5 for the findings of a comparative case study analysis of seven provinces published online at *BMC Health Services Research*.

**'Health consequences to immigrant family caregivers in Canada.'** Scroll down to p.7 for the findings of a study focused on the "double jeopardy" hypothesis and the effect of "reciprocity" published in *Canadian Studies in Population*.

## **U.S.A.**

### **\$1.8 million awarded for palliative care research to improve care of seriously ill patients**

AMERICAN CANCER SOCIETY | Press release – 3 June 2010 – The American Cancer Society and the National Palliative Care Research Center are awarding \$1.8 million in research grants to researchers at 12 institutions for studies aimed at reducing suffering for seriously ill patients and their family caregivers. [http://www.eurekalert.org/pub\\_releases/2010-06/acs-ma060110.php](http://www.eurekalert.org/pub_releases/2010-06/acs-ma060110.php)

### **New hospice, end-of-life laws put Colorado at forefront of care**

COLORADO | *Denver Post* – 3 June 2010 – A host of new Colorado laws intended to expand hospice care and make it easier for people to communicate their dying wishes will push the state to the forefront in end-of-life care, say advocates who asked for the reforms. The legislature rewrote Colorado's Living Will Act so it will apply to those who are in a persistent vegetative state resulting from a terminal illness or a traumatic brain injury. Lawmakers also adopted a standard "medical orders" form – detailing whether to give CPR, artificial nutrition or antibiotics – intended to follow a person from a house to a nursing home to a hospital and back. And the state passed a law to allow the dying to receive insurance-covered hospice care at an earlier stage – when a doctor says they have nine months to live, not just six. The law change needs federal approval before taking effect. The legislature discussed but stopped short of passing a law that would have set up an electronic database containing all the do-not-resuscitate orders in the state. Every hospital, ambulance and doctor's office could access the database to make sure a person's dying wishes – often written in a lawyer's office and then left in a safe at home, unbeknown to caregivers – were followed.

[http://www.denverpost.com/commented/ci\\_15215291?source=commented-](http://www.denverpost.com/commented/ci_15215291?source=commented-)

## Bringing doctors to the dying patient's bedside

*NEW YORK TIMES* | Online article – 3 June 2010 – When D., a woman in her mid-30s, learned that she was dying from complications of AIDS, she fully expected that her life would end in much the same way it had been lived: homeless, alone and among strangers. If it hadn't been for Dr. Jason K. Alexander, a medical student at the time, she might have been right. Two years earlier Dr. Alexander, along with four other classmates, had created a project that paired medical students with patients who were dying alone. "We wanted to reach out to patients who had been shunned, the people others didn't want to deal with," Dr. Alexander recalled. The program, which also helps family members who are struggling with terminally ill loved ones, was part of an innovative new center for humanism at the University of Medicine & Dentistry of New Jersey-New Jersey Medical School in Newark. <http://www.nytimes.com/2010/06/03/health/03chen.html>

## International

### Health staff would like to die at home

*IRISH INDEPENDENT* | Online report – 7 June 2010 – The proportion of health staff who would prefer to die in their own home than in a hospital is greater than in the general population, according to a new audit. The Irish Hospice Foundation found that 81% of ward staff and 77% of other hospital workers, including doctors and nurses, would like to die at home. This contrasts with the same wish expressed by 67% of the general population, the National Audit of End-of-Life Care in Hospitals has revealed. <http://www.independent.ie/health/health-staff-would-like-to-die-at-home-2210360.html>

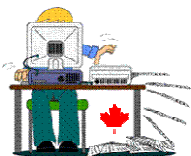
### Das lange Leid der Erika K.

GERMANY | *Welt* – 2 June 2010 – Eine Wachkoma-Patientin wird künstlich ernährt. Ihre Kinder und der Arzt wollen sie sterben lassen. Das Heim weigert sich. Am Ende wird der Anwalt der Familie wegen Totschlags verurteilt. Heute rollt der Bundesgerichtshof den Fall neu auf. <http://www.welt.de/die-welt/vermischtes/article7879409/Das-lange-Leid-der-Erika-K.html>

**N.B.** Germany's Federal Court of Justice (Bundesgerichtshof) is expected to rule this month on whether the removal of artificially administered food and water constitutes murder or is simply the cessation of "medical treatment."

### Palliative care doesn't stop at death

MALAYSIA | *Daily Express* – 1 June 2010 – Clinical Director of Palliative Care Service, Dr. Carol Douglas, from the Royal Brisbane & Women's Hospital, Australia, said care of the family doesn't stop at death of one member. "We continue to be concerned about the family's welfare. They are grieving and grieving is different for every single family. One member of the family might be very accepting and peaceful and the next member might be distressed for a long time. It depends on the relationship [with the deceased]. <http://www.dailyexpress.com.my/news.cfm?NewsID=72825>



### Barry R. Ashpole

My involvement in palliative and end-of-life care dates from 1985. As a communications specialist, I've been involved in or responsible for a broad range of initiatives at the community, regional, provincial and national level. My work focuses primarily on advocacy, capacity building and policy development in addressing issues specific to those living with a life-threatening or terminal illness – both patients and families. In recent years, I've applied my experience and knowledge to education, developing and teaching on-line and in-class courses, and facilitating issue specific workshops, for frontline care providers.

## Anger after doctors put 'Do Not Resuscitate' note on records

U.K. | *Yorkshire Post* – 31 May 2010 – A daughter has told of her "outrage" after discovering doctors treating her late mother did not plan to resuscitate her if she collapsed. Barbara Evans was treated at St James's Hospital in Leeds on a number of occasions during 2006 and 2007 after being diagnosed with a tumour on her liver. But her daughter Caroline Feeman said she was shocked to later discover DNR (Do Not Resuscitate) had been written on her medical notes during one 17-day stay on an elderly care ward in July 2006. The issue is being highlighted in new guidance on end-of-life care which comes into force in July.<sup>1</sup> Campaigners have welcomed guidelines drawn up by the General Medical Council which emphasise that patients must be given an opportunity to discuss their wishes but still give doctors the right to exercise

their own judgment in making DNR decisions (see sidebar below).

<http://www.yorkshirepost.co.uk/news/Anger-after-doctors-put-39Do.6331334.jp>

### The General Medical Council guidelines state:

Following established ethical and legal (including human rights) principles, decisions covering potentially life-prolonging treatments must not be motivated by a desire to bring about a patient's death and must start with a presumption in favour of prolonging life. This presumption will normally require you to take all reasonable steps to prolong a patient's life. However, there is no absolute obligation to prolong life irrespective of the consequences for the patient, and irrespective of the patient's views, if they are known or can be found out.

From Media Watch dated 24 May 2010:

U.K. | *Daily Telegraph* – 20 May 2010 – '**Doctors must respect wishes of terminal patients 'to refuse treatment and die.'** Mandatory new rules drawn up by the General Medical Council warn medics that they must not ignore the wishes of dying patients who do not want their lives prolonged. <http://www.telegraph.co.uk/health/healthnews/7741046/Doctors-must-respect-wishes-of-terminal-patients-to-refuse-treatment-and-die.html>

## Assisted (or facilitated) death

Representative sample of recent news media coverage:

- U.K. | *Daily Telegraph* – 3 June 2010 – '**Disability campaigner ... urges MPs not to relax assisted suicide law.**' A leading disability rights campaigner is spearheading a campaign urging MPs not to relax laws on assisted suicide. <http://www.telegraph.co.uk/news/uknews/law-and-order/7798414/Disability-campaigner-Baroness-Campbell-urges-MPs-not-to-relax-assisted-suicide-law.html>
- SWITZERLAND | *Daily Mail* (U.K.) – 31 May 2010 – '**Swiss suicide clinic Dignitas probed after 'patient suffering from paranoid schizophrenia was given suicide kit.'**' Strict assisted suicide laws in Switzerland state that each patient must be of sound mind and able to understand the consequences of their actions. <http://www.dailymail.co.uk/news/worldnews/article-1282912/Dignitas-probed-patient-suffering-paranoid-schizophrenia-given-suicide-kit.html>

### Quotable Quotes

*Five times in my life I've sat at the bedside of a friend or relative dying in a crowded Irish hospital ward, appalled at the lack of privacy and dignity endured both by the dying and their loved ones. But as I sat with my friend I asked myself – why does it have to be like this? Is there anything I can do to change this awful situation? To die with dignity is a right, not a privilege.*

**Actor Gabriel Byrne, Patron of the Irish Forum on End of Life**

## [Specialist Publications \(e.g., in-print and online journal articles, reports, etc.\)](#)

### **Reflections on the under-researched topic of grief in persons with dementia: A report from a symposium on grief and dementia**

*AMERICAN JOURNAL OF HOSPICE & PALLIATIVE MEDICINE* | Online article – 4 June 2010 – This article describes a symposium about the clinical challenges of providing care to persons with dementia and their families. The plenary session addressed the bereavement process in the general older adult population, neurocognitive processes that alter the grief process in persons with dementia, and therapeutic approaches to support grieving persons in different stages of dementia. <http://ajh.sagepub.com/cgi/content/abstract/1049909110371315v1>

### **Meaning in life in patients with amyotrophic lateral sclerosis**

*AMYOTROPHIC LATERAL SCLEROSIS* | Online article – 17 March 2010 – The construct 'meaning in life' (MiL) has become increasingly important in palliative care. Several meaning-focused interventions have been developed recently. The aim of this study was to investigate MiL in patients with amyotrophic lateral sclerosis (ALS) and compare the findings with a representative sample of the German population. Compared to the general population, ALS patients list more meaning-relevant areas, are more likely to list partner, and less likely to list health. Thus, response shift seems to be a central coping mechanism in ALS patients. Regarding their major MiL areas, they shift their focus away from decreasing health status and towards supportive relationships. <http://informahealthcare.com/doi/abs/10.3109/17482961003692604>

### [End-of-life issues for the elderly](#)

#### **It is time for our generation to act courageously**

*ASSOCIATION FOR DEATH EDUCATION & COUNSELING*, 2010;36(2):1,3-5. Extraordinary times demand extraordinary action. Such times also bring extraordinary opportunities. Caring well for the unprecedented numbers of elderly and chronically ill people who are facing the end-of-life will require – already requires – strong, clear social and political actions. We can draw strength from our core values and guidance from the principles which undergird our professions. They will not fail us. More importantly, in acting from our values and principles, we will not fail the people and society we serve. <http://www.dyingwell.org/downloads/ADECForum0410.pdf>

### [Comparative case study analysis of seven provinces](#)

#### **Tracking the evolution of hospice palliative care in Canada**

*BMC HEALTH SERVICES RESEARCH* | Online article – 1 June 2010 – Findings point to the fact that hospice palliative care (HPC) continues to remain at the margins of the health care system. Its development has encountered structural inheritances that have both sped up progress as well as slowed it down: 1) foundational health policies (e.g., the Canada Health Act); 2) service structures and planning (e.g., the dominance of urban-focused initiatives); and, 3) health system decisions (e.g., regionalization). As a response, circumventions of the established system of care were taken, often out of necessity. Three kinds of circumventions were identified from the data: 1) interventions to shift the system (e.g., the role of advocacy); 2) service innovations (e.g., educational initiatives); and, 3) new alternative structures (e.g., the establishment of independent hospice organizations). Overall, the evolution of HPC across the case study provinces has been markedly slow, but steady and continuous. Though demographics are expected to influence HPC demand in Canada, our study confirms that concerned citizens, advocacy organizations and local champions will continue to be the agents of change that make the necessary and lasting impacts on HPC in Canada. <http://www.biomedcentral.com/content/pdf/1472-6963-10-147.pdf>

## Barriers and needs in paediatric palliative home care in Germany

*BMC PALLIATIVE CARE* | Online article – 2 June 2010 – In this qualitative interview study with professional experts, predominant barriers were seen in the lack of clear legal and financial regulations which take into account the specific challenges of palliative care in children and adolescents, as well as in a shortcoming of specialist services for a local based care provision throughout the federal country. <http://www.biomedcentral.com/content/pdf/1472-684x-9-10.pdf>

Of related interest:

- *BMC PALLIATIVE CARE* | Online article – 4 June 2010 – '**Paediatric palliative home care by general paediatricians: A multimethod study on perceived barriers and incentives.**'  
Altogether, the high commitment to this survey reflects the relevance of the issue for paediatricians working in general practice. Education in basic palliative care competence and communication skills was seen as an important prerequisite for the engagement in paediatric palliative home care. A local network of specialist support on site and a 24/7 on-call service are necessary in order to facilitate the implementation of basic palliative care by paediatricians in their own practice. <http://www.biomedcentral.com/content/pdf/1472-684x-9-11.pdf>
- *CHIPPS PEDIATRIC PALLIATIVE CARE NEWSLETTER* | Online publication – May 2010 – '**Pediatric hospice and palliative care in the United States: The current state of the art.**'  
[http://www.nhpc.org/files/public/Chipp/ChiPPS\\_ews-19\\_May\\_2010.pdf](http://www.nhpc.org/files/public/Chipp/ChiPPS_ews-19_May_2010.pdf)

## Destined to die in hospital? Systematic review and meta-analysis of place of death in haematological malignancy

*BMC PALLIATIVE CARE* | Online article – 1 June 2010 – Haematological malignancies are a common, heterogeneous and complex group of diseases that are often associated with poor outcomes despite intensive treatment. Research surrounding end-of-life issues, and particularly place of death, is therefore of paramount importance, yet place of death has not been formally reviewed in these patients. Home is generally considered the preferred place of death but haematology patients usually die in hospital. This has implications for patients who may not be dying where they wish, and also health commissioners who may be funding costly end-of-life care in inappropriate acute hospital settings. More research is needed about preferred place of care for haematology patients, reasons for hospital deaths, and how these can be avoided if home death is preferred. <http://www.biomedcentral.com/content/pdf/1472-684x-9-9.pdf>

### [Media Watch Online](#)

The weekly report can be accessed at several websites, among them:

#### **Canada**

Ontario | Hamilton Niagara Haldimand Brant Hospice Palliative Care Network:  
<http://www.hnhbhpc.net/Resources/UsefulLinks/MediaWatch/tabid/97/Default.aspx>

Ontario | HPC Consultation Services:  
<http://www.hpcconnection.ca/newsletter/inthenews.html>

#### **U.S.A.**

*Prison Terminal*:  
<http://www.prisonterminal.com/news%20media%20watch.html>

#### **International**

Global | Palliative Care Network Community:  
<http://www.pcn-e.com/community/>

U.K. | Omega, the National Association for End of Life Care: <http://www.omega.uk.net/media-watch-provides-global-roundup-of-end-of-life-issues-n-96.htm>

## Health consequences to immigrant family caregivers in Canada

*CANADIAN STUDIES IN POPULATION*, 2010;37(1-2):107-124. About 16% of immigrants and 13.6% of non-immigrants said that their health was negatively affected as a result of caregiving. Immigrant family caregivers were three times more likely than non-immigrants to report a health consequence. Reciprocity played a big role in this outcome. Given the fact that an increasing number of culturally diverse immigrants enter Canada every year and that the immigrant population is aging, more caregivers will be in demand. Policy makers need to find ways to keep immigrant caregivers healthy so that quality care can be given to immigrant older adults and also for maintaining an overall healthy Canada. <http://www.canpopsoc.org/journal/2010/CSPv37n1-2p107.pdf>

## An exploration into the palliative and end-of-life experiences of carers of people with Parkinson's disease

*PALLIATIVE MEDICINE* | Online article – 4 June 2010 – The aim of this study was to explore former carers' lived experiences of palliative and end-of-life care. Findings indicated that some palliative and end-of-life care needs had not been fully addressed. Lack of communication, knowledge and coordination of services resulted in many people caring for someone with Parkinson's disease not accessing specialist palliative care services. Participants also reflected upon the physical and psychological impact of caring in the advanced stage of Parkinson's. A multi-disciplinary team-based approach was advocated by participants. According to palliative care standards, patients and their carers are the unit of care; in reality, however, this standard is not being met. <http://pmj.sagepub.com/cgi/content/abstract/0269216310371414v1>

From Media Watch dated 10 August 2009:

- *CHRONIC ILLNESS*, 2009;5(1):46-55. **'Palliative care and Parkinson's disease: Managing the chronic-palliative interface.'** The author's analysis centers on palliation for Parkinson's disease because it illustrates the difficulties of managing the chronic-palliative interface, and it also demonstrates how care is situated in an evolving network of professional and non-professional actors. <http://chi.sagepub.com/cgi/content/abstract/5/1/46>

From Media Watch dated 16 March 2009:

- *PALLIATIVE MEDICINE*, 2009;23(2):120-125. **'Palliative stage Parkinson's disease: Patient and family experiences of health-care services.'** Findings (of this study) support previous research that indicate palliative care needs are not being met in the current health-care model and that palliative care services should be multi-disciplinary, team-based in order to provide comprehensive support to both patients and families. <http://pmj.sagepub.com/cgi/content/abstract/23/2/120>

## Ethical challenges in the provision of end of life care in Norwegian nursing homes

*SOCIAL SCIENCE & MEDICINE* | Online article – 26 May 2010 – Inadequate care due to lack of resources and breaches of the patient's autonomy and integrity were the ethical challenges reported most often in this study. Conflicts with the next of kin regarding nursing care and termination of life-prolonging treatment were reported more seldom. However, when asking the respondents to outline one of the most recent ethical dilemmas they had encountered, the majority of the respondents described ethical dilemmas concerning limitation of life-prolonging treatment, often mixed with disagreements between the wish of the family and that of the patient, or between the wish of the next of kin and what the staff consider to be right. Ethical dilemmas associated with breaches of the patient's autonomy and integrity were also thoroughly described. [http://www.sciencedirect.com/science?\\_ob=ArticleURL&\\_udi=B6VBF-505F9S7-1&\\_user=10&\\_coverDate=05%2F26%2F2010&\\_rdoc=1&\\_fmt=high&\\_orig=search&\\_sort=d&\\_docanchor=&view=c&\\_searchStrId=1360280026&\\_rerunOrigin=scholar.google&\\_acct=C000050221&\\_version=1&\\_urlVersion=0&\\_userid=10&md5=31b0b5a3dfad68aac18d23a7d047f1ec](http://www.sciencedirect.com/science?_ob=ArticleURL&_udi=B6VBF-505F9S7-1&_user=10&_coverDate=05%2F26%2F2010&_rdoc=1&_fmt=high&_orig=search&_sort=d&_docanchor=&view=c&_searchStrId=1360280026&_rerunOrigin=scholar.google&_acct=C000050221&_version=1&_urlVersion=0&_userid=10&md5=31b0b5a3dfad68aac18d23a7d047f1ec)

## Worth Repeating

### **Improving end of life care for chronic heart failure patients – "Let's hope it'll get better, when I know in my heart of hearts it won't"**

*HEART* | Online article – 19 February 2007 – [In a series of interviews] patients and families reported a wide range of end of life care preferences. None had discussed these with their clinicians, and none were aware of choices or alternatives in future care modalities, such as adopting a palliative approach. Patients and carers live with fear and anxiety, and are uninformed about the implications of their diagnosis. Cardiac staff confirmed that they rarely raise such issues with patients. Disease specific and specialism-specific barriers to improving end of life care were identified. This novel, integrated data provides three recommendations for improving care in line with policy directives: sensitive provision of information and discussion of end of life issues with patients and families; mutual education of cardiology and palliative care staff; and, mutually agreed palliative care referral criteria and care pathways for chronic heart failure patients.  
<http://heart.bmj.com/content/early/2007/02/19/hrt.2006.106518.abstract>

### Media Watch: Editorial Practice

Each listing in Media Watch represents a condensed version or extract of what is broadcast, posted (on the Internet) or published; in the case of a journal article, an edited version of the abstract or introductory paragraph, or an extract. Headlines are as in the original article, report, etc. There is no editorializing ... and, every attempt is made to present a balanced, representative sample of "current thinking" on any given issue or topic. The weekly report is issue-oriented and offered as a potential advocacy tool or change document.

### Distribution

Media Watch is distributed at no cost to colleagues active or with a special interest in hospice, palliative care and end of life issues. Recipients are encouraged to share the weekly report with *their* colleagues. The distribution list is a proprietary one, used exclusively for the distribution of the weekly report and occasional supplements. It is not used or made available for any other purpose whatsoever – to protect the privacy of recipients and also to avoid generating undue e-mail traffic.

### Links to Sources

1. Links are checked and confirmed as active before each edition of Media Watch is distributed.
2. Links often remain active, however, for only a limited period of time.
3. Access to a complete article, in some cases, may require a subscription or one-time charge.
4. If a link appears broken or inactive, try copying/pasting the URL into the address bar of your browser or, alternatively, Google the title of the article or report, and the name of the source.
5. Due to its relevance, an article may be listed but for which a link is not available; access, therefore, may only be possible directly from the source (e.g., publication) or through the services of a library.

### Something Missed or Overlooked?

If you are aware of a current report, article, etc., relevant to hospice, palliative care or end-of-life issues not mentioned, please alert this office (contact information below) so that it can be included in a future issue of Media Watch. Thank you.

---

**Barry R. Ashpole**  
Beamsville, Ontario CANADA

'phone: 905.563.0044  
e-mail: [barryashpole@bellnet.ca](mailto:barryashpole@bellnet.ca)