



# Perspectives 2004

THE DE VEBER INSTITUTE FOR BIOETHICS AND SOCIAL RESEARCH

*Research and Scholarship for an Informed Social Response to Human Life Questions*

## interviews

### If I could find a way to tell you ...

by Denyse O'Leary

Does a bioethics institute risk seeing only the societal issues around medicine, abstracted from the human beings who are the patients? *Perspectives* asked doctors and nurses associated with the deVeber Institute a searching question: Tell us one thing that you wish your patients knew that you cannot really tell them, perhaps because they won't believe you? Some of the surprising answers demonstrate the way in which rapid medical advances have created communication gaps.



#### Barrie deVeber

#### Accept That Your Child's Cancer CAN Be Cured, Doctor Counsels

Barrie deVeber, formerly the director of Paediatric Oncology for the Children's Hospital of Western Ontario, found that the biggest challenge for his practice was getting the parents to accept that their child would probably be cured. However, by the time Barrie left paediatric oncology, the cure rate was actually 85%. Thus, his challenge was not the traditional one, of counselling parents who have unrealistic hope, but rather a new one - counselling parents who have unrealistic despair.

The time lag in public perception of medical advances can lead to frightening outcomes. For example, in one case, the parents, discouraged by the relatively poor prognosis and the severe side effects of chemotherapy, requested euthanasia as they were unconvinced their child had any chance of survival, he recalls. Barrie, of course, refused,

but the next morning, the girl told him that she knew of her parents' plans. What she - and they - didn't know was that she would make a complete recovery. She now has children of her own, but she also has the memory of this completely unnecessary trauma.

In Barrie's current bereavement practice, the greatest "if only I could find a way to tell you" challenge is to help bereaved spouses who feel inappropriately responsible for the death of the loved one to accept reality. He can best help them, he finds, by going over the events in detail, until they come to see that they could not really have prevented it.



#### Nancy Olivieri

#### Understand That Some Health Problems Stem from Political Decisions, Doctor Explains

Nancy Olivieri, a specialist in blood diseases with the University Health Network, Toronto General Hospital - and well known for her courageous stand against drug company manipulation of science

research - says that her patients have “a trust in the medical system that is pretty well unfounded, or ill-founded. They sense that there is a body of authority that is licencing and making available drugs that are tested as safe by scientists. And that simply isn't the case.”

Health Canada has moved over the years from a “proof of safety” criterion to a more risky “proof of harm” criterion, she notes. While she can explain this to patients who face difficult drug choices, it is not easy to get them to understand the implications.

She cites, for example, a recent *New York Times* story (June 3, 2004) which reveals that two studies were done during the mid-1990s for drug company SmithKline Beecham, on the antidepressant Paxil. One study said Paxil helped depressed teens, and the other said it didn't. But the company publicized only the first study. The affair came to light when independent researchers discussed the second study at a conference. New York State is now suing the pharmaceutical company.

Some Canadians may be tempted to imagine that such things do not happen in Canada. On the contrary, says Nancy, the difference between Canada and the US does not flatter Canada. “The FDA still has some semblance of control whereas Health Canada has been eroding its precautionary principles approach for decades.” The challenge, she says, is the great wealth and power of pharmaceuticals, but again, that is a difficult issue to discuss with patients without appearing to politicize health care.

## Jean Echlin

Picture of  
Jean Echlin  
goes here.

### Don't Ignore the Spiritual Dimensions of Pain, Nurse Warns

Jean Echlin, a nursing consultant in palliative care in London, Ontario, offers, “I wish people knew how enormous the spiritual dimension of pain is!” People who have never taken spiritual issues seriously “seem to have more issues at the end of life.” As a palliative care worker who started during the “pioneer” phase in 1979, she has seen great progress in the medical side of pain management. However, she finds, lack of spiritual resources for coping with terminal illness can mean that people suffer a great deal in ways in which a purely medical system is not equipped to help them.

The problem is aggravated by an increasing shortage of chaplaincy services at many hospitals. Jean recalls one man who had a profound religious experience at the end of his life, but Jean had great difficulty even *interesting* a chaplain in visiting him. Ironically, chaplaincy services are diminishing at the very time when society shows an increasing interest in spiritual issues.

Overall, medical professionals find that some truths cannot be communicated in words alone. They must walk with the patient through the illness and its outcome, so that the patient and loved ones can understand what the words mean.



Denyse O'Leary ([www.designorchance.com](http://www.designorchance.com)) is the author of *By Design or by Chance?* (Augsburg Fortress 2004), as well as many articles on science and bioethics issues.

## End-Of-Life Issues and Post-Abortion Grief

Over the last 25 years, I have been honoured to work as a nursing consultant in palliative hospice care. This has given me the opportunity to walk beside more than one

thousand individuals and their families as they face what is often the chaos and crisis of dying.

In providing palliative and/or hospice care, all members of the health care team follow a model or conceptual framework that began in Great Britain during the 1960s with the development of St. Christopher's Hospice, London. Dr. Cicely Saunders, a brilliant and compassionate physician built St. Christopher's Hospice

with the help of young man who was dying.

Dr. Saunders taught the concept of "total pain." This encompassed the physical, emotional, social, and spiritual pain suffered by individuals facing a life-threatening or terminal illness. Management of the whole person has remained a cornerstone in this newer health care reform. All who practice nursing, medicine, pastoral care and social work in the palliative hospice setting, build patients' needs around Dame Cicely's model.

When physical pain is managed, there is room for the person to face the issues of importance in their lives prior to death. One of the biggest issues for everyone is their concern about life after death and whether they will "qualify". This brings into focus the person's spirituality, beliefs and values, or total lack of a belief system.

Amazingly, the entire realm of spiritual issues is so overwhelming that it may cause physical pain or emotional anxiety to escalate. Further, no amount of pain medication or treatment for anxiety helps.

Nothing I have seen prepared me for the psychospiritual pain suffered by women who had obtained an abortion during their lifetimes. An alarming amount of physical pain was unmanageable until this issue was confronted by women who ranged in age from 19 to 96 at the time that they were dying. There were 23 women whom I encountered, and likely many who went to their graves without comfort and a sense of forgiveness.

Some women were married and had their abortion after delivery of one or more children. Some were single. Some did so at the request or insistence of their husbands, boyfriends and fiancés, and one at the insistence of her mother.

With both young and elderly patients, there was a pervasive theme of fear, guilt, and shame. Many of the older women described seeing a developing child in the uterus on a TV program. Again the mothers experienced

profound anxiety and distress. "My baby had arms and legs, fingers and toes, a face and even a sucking movement with the mouth. I had no idea that the baby would be so fully formed at just a few weeks!" Younger women expressed feelings of depression and having wished themselves dead at times.

In essence, the amelioration of psychospiritual pain includes quiet, thoughtful discussion, and the use of "therapeutic presence." In addition, a person in late-stage or terminal illness must be open to address the most troublesome of life issues. Several of the women I followed did come to a sense of forgiveness and peace prior to their death.

To my knowledge there is a paucity of research and literature regarding the issue of abortion at the end-of-life, and from the cases I have seen in my nursing practice, I believe this merits further investigation.

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ANNUAL GENERAL MEETING  
September 26, 2004

Information about the Institute's upcoming  
AGM will be posted on [www.deveber.org](http://www.deveber.org)  
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### Our Vision

Research and Scholarship for an Informed Social Response to Human Life Questions

### Our Mission

The deVeber Institute for Bioethics and Social Research conducts and disseminates research on topics connected to human life in its biological, social and ethical dimensions. The topics selected for study depend on emerging medical, technological and social developments. In undertaking this work the Institute believes that a sense of the inherent value and dignity of human life and of the human person as an end and not a means is a foundational perspective it brings to its work.



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## Wally Bedolfe

We record with regret the passing of Wally Bedolfe, a warm friend and generous supporter of the Institute. Wally belonged to an organization of business people in Toronto who met once a month to discuss current issues and to give practical support to worthwhile causes. Two members of the Institute, Dr Paul Ranalli and Professor Ian Gentles, were invited to address his group. We extend our sincere sympathy to Wally's family. He will be sadly missed.

## *Women's Health after Abortion, Third Edition*

Since the abundance of emerging international studies challenges us to sustain our research examining the effects of abortion on women, men, and children, the Board of Directors has committed to a third edition of *Women's Health after Abortion*.

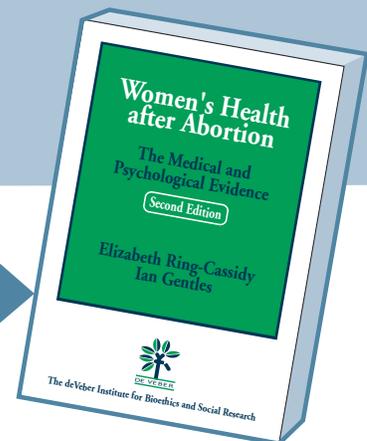
In preparation for this initiative we designated a portion of financial gifts to the acquisition of a specialized bibliographic program and computer upgrade.

Foundational funding is vital to this comprehensive research. We begin our fundraising by asking you, our readers and supporters, for financial assistance. Your donations affirm your confidence in the importance and worthiness of the Institute's vision.

We expect the base research will take two years and \$70,000 to start, though the time and cost depend on the research details uncovered during the process.

We credit many individuals who contribute considerable volunteer hours – without their gracious gifts of time and expertise, costs would rise substantially.

The deVeber Institute is the only Canadian organization continuously researching abortion sequelae, and we thank our donors for making this possible.



Women's Health after Abortion costs \$24.95 Canadian or \$19.95 US, plus \$8.00 for shipping.  
Contribute \$75 and receive a complimentary copy along with an income tax receipt. See order form attached.