

When Answers Are Everything

2002/03 - 2005/06 SUMMARY REPORT



CANADIAN VIRTUAL HOSPICE

CARREFOUR VIRTUEL CANADIEN DES SOINS PALLIATIFS

> www.virtualhospice.ca www.carrefourpalliatif.ca

MISSION

TO ENHANCE AND FACILITATE ACCESS TO PALLIATIVE CARE INFORMATION AND SUPPORT FOR CANADIANS WITH LIFE-THREATENING ILLNESSES, THEIR FAMILIES AND FRIENDS; HEALTH CARE PROFESSIONALS, VOLUNTEERS AND RESEARCHERS, THROUGH A COMPREHENSIVE, INTERNET-BASED NETWORK.

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Why a Canadian Virtual Hospice?

A LETTER FROM THE CHAIR AND EXECUTIVE DIRECTOR

IN SIMPLEST TERMS, the Canadian Virtual Hospice is a network of information and support related to death and dying. But, for the people who find reassurance, new understanding and a feeling that they are not alone in difficult times, this online community is so much more.

www.virtualhospice.ca was born out of the recognition that palliative care services in Canada are very often fragmented, with regional disparities and marked differences in the care available in urban centres compared to rural or northern communities. Palliative care, with its focus on providing comfort during the final stages of life, will only become more relevant as Canada's population ages. According to Statistics Canada, the proportion of seniors in the overall population has grown from one in twenty in 1921, to one in eight in 2001. By 2041, nearly one in four Canadians will be aged 65 or older. This aging population is sure to intensify the pressure placed upon our hospice and palliative care services. At the same time, Canadians of all ages are becoming increasingly familiar with the philosophy of palliative care and have heightened expectations for comprehensive, guality end-of-life services in their own homes and communities.

www.virtualhospice.ca is an innovative response to these palliative care realities. Created by Canadians, for Canadians, this bilingual website overcomes the challenges of distance and geography, providing equal access to palliative care resources and health care professionals while taking full advantage of current technology. The overriding goals are to provide accurate, timely health information and to introduce Canadians with similar experiences to each other. Like a hospice made of bricks and mortar, we provide information and support for physical, emotional and spiritual concerns related to death and dying. Imagine that you are the parent, brother, sister or child of someone who is seriously ill. Consider the value of the Canadian Virtual Hospice when:

- you are feeling overwhelmed and confused that a loved one will not eat, but reading about loss of appetite in Symptoms of Illness at www.virtualhospice.ca gives you a new understanding of some of the physical changes that are taking place, allaying your fears and allowing you to focus on making the most of the time you have left together
- you are worried that a family member with irregular breathing is suffering so you submit a question to Ask a Professional at www.virtualhospice.ca and learn from our health care team that certain breathing patterns are expected as death nears and do not necessarily indicate pain or suffering
- you have just learned there is no treatment to extend the life of someone you care about, so you turn to the Bulletin Board at www.virtualhospice.ca and find solace in the words of other Canadians who respond to your question about coping

Sometimes answers to questions like these hold great significance, especially for those who are concerned about the well-being of a loved one, but are hesitant or unsure about how to help. It's not only patients, family members and friends who are drawing upon the Canadian Virtual Hospice. Canadian health care professionals are spreading the word among their peers that access to expert opinion on palliative care is available at www.virtualhospice.ca. Physicians, nurses and other health care providers are coming to Ask a Professional to be sure that they are providing the very best care for their patients.

You have made such a **positive difference** in our lives! Without the site

my husband and I would literally be alone in all this!





Thank you so much for not just the information but your kindness in answering

me so promptly. Thank you again - I only wish I had the words to fully express how much this means.



The theme When Answers Are Everything seemed appropriate for this summary report, given the feeback we have received from Canadians stressing that www.virtualhospice.ca makes an important contribution at a difficult time of life. You will see some of that feedback throughout this report.

As Chair and Executive Director of the Canadian Virtual Hospice, we are privileged to be involved in a national initiative that holds such meaning for Canadians. We have recently renewed our funding partnership with the Government of Manitoba, which will assist the Canadian Virtual Hospice in developing its long-term vision. With this financial commitment, the first order of business is to ensure that more Canadians know about us so that they may benefit from the resources we have to offer. The second is to consider new opportunities for collaboration and expansion of our resources. The Internet is a dynamic environment and the Canadian Virtual Hospice intends to embrace innovation to ensure that Canadians have the best possible access to the tools that may better equip them to deal with life-threatening illness and loss.

Finally, we would like to acknowledge the contribution of Anita Stern, former Co-Chair of the Canadian Virtual Hospice. Anita's vision and commitment to creating an interactive space for those touched by life-threatening illness or loss were inspiring to everyone involved in this project. Thank you, Anita for your tireless support.

by 1 alli

Harvey Max Chochinov, OM, FRSC Chair, Canadian Virtual Hospice

Josette Buard

Josette Bérard, BA, MPA Executive Director, Canadian Virtual Hospice

Thank you so much for your quick reply. My anxiety has been reduced immensely...

help and comfort



Who We Are

WWW.VIRTUALHOSPICE.CA IS A bilingual

resource offered at no charge to all Canadians. It is an interactive network of information and support for people dealing with life-threatening illness and loss.

The Canadian Virtual Hospice went online in 2004, after three years of planning and development. Led by Co-Chairs Anita Stern in Hamilton and Dr. Harvey Chochinov in Winnipeg, the launch of www.virtualhospice.ca was the result of collaboration among leading Canadian palliative care clinicians, academics and researchers.

The Canadian Virtual Hospice is managed by an Executive Director and staffed by a health care team, including palliative care physicians and clinical nurse specialists.

The National Advisory Committee, made up of health care professionals from around the country, provides regular feedback and input to the management team.

Funded initially by Western Economic Diversification Canada, Manitoba Health, Riverview Health Centre in Winnipeg and, Health Canada's Office of Health and the Information Highway, the Canadian Virtual Hospice also received administrative and in-kind support from CancerCare Manitoba and the Winnipeg Regional Health Authority.

Recently, the Manitoba Government has made significant financial contributions through Manitoba Health and Manitoba Energy, Science and Technology.

What We Do

PROVIDE ANSWERS WHEN ANSWERS ARE EVERYTHING

PALLIATIVE CARE IS an approach to care which focuses on comfort and quality of life for those who are affected by life-threatening illness. Its goal is much more than comfort in dying, however. Palliative care is about living, through meticulous attention to symptom control and efforts to maximize day-to-day functioning.

As illness progresses, most people face numerous physical, psychosocial and spiritual challenges and may at times feel confused, fearful and uncertain. Meeting the emotional needs of the patient, as well as the physical needs, is a key component of palliative care. Everyone approaches the end of life differently, but research (*Singer, P.*) has shown that most people have similar concerns, including:

- receiving adequate pain and symptom management
- avoiding inappropriate prolongation of dying
- achieving a sense of control
- relieving burden on others
- strengthening relationships with loved ones

Each one of these concerns raises a number of questions, not only from patients, but also from family members and friends. Not surprisingly, these questions don't always come to mind at an opportune time, when everyone is thinking clearly and a health care professional is on hand. Yet, the need for information and support is palpable. When answers are everything, www.virtualhospice.ca is there to help. The Canadian Virtual Hospice provides answers several different ways, starting with Ask a Professional. This webbased service allows anyone, from patient to health care professional, to put questions to Canadian Virtual Hospice palliative care experts. The health care team provides insightful, detailed responses to these questions, often on the same day the questions are received.

Frequently Asked Questions is a collection of questions drawn from the experiences of palliative care doctors and nurses. The questions and answers can be searched by category or by keyword, helping users zero in on the right answer. Frequently Asked Questions enables patients, family members and friends to access information on common questions at any time of the day or night.

The Information sections cover clinical, psychosocial and spiritual matters, providing a level of detail not often found on health care sites targeted at consumers. Topics dealing with symptoms of illness, such as pain, shortness of breath, and dehydration provide the latest treatment options and can be used to improve discussions with the local health care team. For example, after reading the information on the site, patients and family members may gain an understanding of why certain symptoms develop, so that they can better understand why some treatments are more appropriate than others. The site's powerful search engine identifies and conveniently sorts all the resources available on www.virtualhospice.ca.

In its first two years of operations, the Canadian Virtual Hospice received more than 69,000 visits.

I am just so lucky to have found this site, as it has helped me to

answer questions

have concerning my grandmother



THE MOST FREQUENT USERS OF ASK A PROFESSIONAL ARE:

health care professionals asking about their patients

 ordinary Canadians asking about family members

CREATE A COMMUNITY

THE CREATORS OF the Canadian Virtual Hospice were very deliberate in their efforts to make www.virtualhospice.ca a place where Canadians could gather and share their experiences. Many Canadians feel uncomfortable talking about death and dying, inadvertently increasing the sense of isolation people directly affected by illness experience. In addition to providing reliable information, the purpose of the Canadian Virtual Hospice is to connect people with others who are dealing with similar circumstances and understand just how they feel.

It is striking how people use the Bulletin Board and Online Chat to seek out people who have been in similar situations. They may be surrounded by people who love and care for them, but ultimately, they feel a need to connect with people in like circumstances. In addition, people may feel freer revealing their feelings online because of the anonymity and sense of emotional safety that comes from speaking with virtual friends. Providing the forum for these connections and discussions is the role of www.virtualhospice.ca. As awareness of this resource increases, these interactive areas are expected to see significant increases in traffic. The Virtual Hospice health care team has noted that relationship-building among clinicians and researchers is one of the unexpected results from Ask a Professional. The health care team acts as a hub, connecting Canadian health care professionals with each other, sometimes leading to new collaboration in palliative care.

Members of the health care team take care to ensure the Canadian Virtual Hospice has a presence in the health care community across the country. For example, members of the multidisciplinary team attend professional palliative care conferences, make presentations about their work and have tapped into tele-health networks in order to increase the profile of the Canadian Virtual Hospice among health care professionals.



Thank you so much for your speedy response! You have really helped me to **Narrow my focus** and concentrate on what is most

DELIVER EXCELLENCE AND EFFICIENCY

THE CANADIAN VIRTUAL HOSPICE

is committed to providing reliable health information. The information on the site has been developed by palliative care specialists and is accurate, straightforward and accessible. Information for Patients covers the potential causes of physical symptoms, lists potential tests that may be required, provides questions the doctor is likely to ask, examines the potential treatments and discusses strategies to deal with symptoms. The information provided to health care professionals through Ask a Professional is detailed, drawing upon recent health care research and often including a list of resources for health care providers to review themselves.

The Canadian Virtual Hospice approach of acting as a hub for all Canadians with questions about palliative care has the potential to be a model for many other disciplines. Although consumers can find doctors working online to answer their health questions, to date these services are largely generalist in nature. Providing expert consultations for both health care professionals and consumers on one site is still a novel approach in health care. Receiving viewpoints and input from users is one means of measuring performance. Everyone who sends a question to Ask a Professional receives a follow-up e-mail with several survey questions. In this way, user satisfaction can be easily monitored and the health care team can quickly adapt as a result of the feedback provided. Overall satisfaction with Ask a Professional stands at 95 per cent, representing a great achievement for the website's health care team.

In addition, the Canadian Virtual Hospice National Advisory Committee, made up of health care professionals from around the country, ensures that regional perspectives are part of the decision-making and evaluation process.

ASK A PROFESSIONAL MEETING USER NEEDS





agree the answer helps in understanding the issues

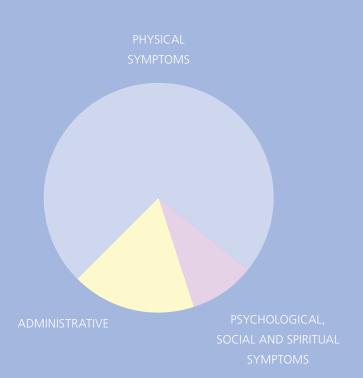


agree the answer will help, or has helped, with making decisions

I hope that when you end your day from work, you know that you are doing something that

reaches someone's soul.

WHAT DO CANADIANS WANT TO KNOW?



The majority of questions submitted to Ask a Professional relate to some aspect of a patient's physical well-being.

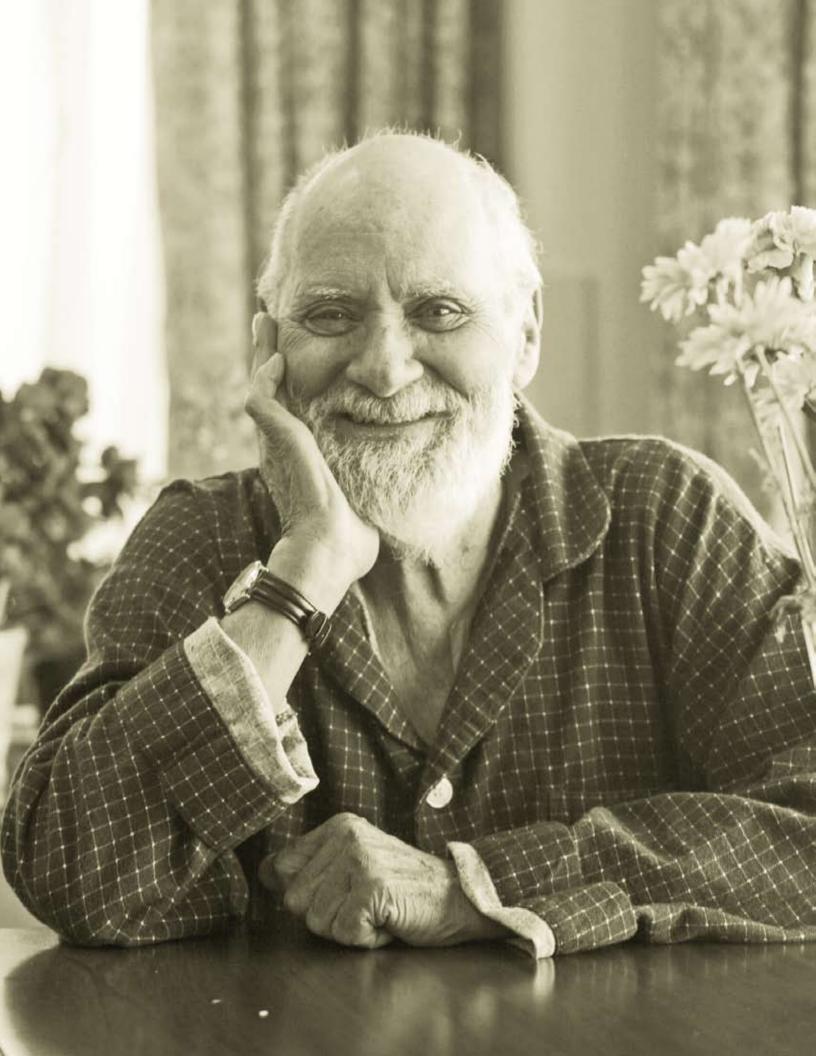
CARE FOR EACH OTHER

THE CANADIAN VIRTUAL HOSPICE epitomizes a cherished component of the Canadian identity: our capacity to care for each other. While the demand for palliative care by Canadians nearing the end of their lives is increasing, there is often no system of comprehensive care in smaller, northern and remote communities, whether that means hospices, palliative care beds in hospitals or health care supports provided in the home. www.virtualhospice.ca is one means of beginning to address these inequalities, providing all Canadians with access to information and support through one common gateway.

The Canadian Virtual Hospice helps people care for each other in many different ways, in a variety of settings. For example, the site supports Canadians who are caring for a dying family member at home by providing appropriate clinical, psychosocial and spiritual information, supports family members who want to increase their knowledge and confidence before speaking with their local health care teams, and supports health care professionals who want to ensure that they are meeting the highest standards of care. The Canadian Virtual Hospice does not attempt to replace existing health care, but works to complement existing resources.

As Canada's population ages and existing resources are stretched to meet the needs of increasing numbers of people requiring palliative care, the services of www.virtualhospice.ca will ensure that Canadians always have somewhere to go for a reassuring word or trustworthy information.





Where We're Going

The Canadian Virtual Hospice is pleased to be associated with many other organizations working to ensure that Canadians are leaders in the field of palliative care. Whether educating future health care professionals or consumers of health care, Canada has some of the most impassioned champions of palliative care in the world. By developing creative partnerships, the Canadian Virtual Hospice expects that the technological strengths of www.virtualhospice.ca can be successfully paired with the content needs identified by partners. Some of these partnership projects include:

- Hosting the Canadian Palliative Care Researcher Database, through the leadership and support of Health Canada's Secretariat on Palliative and End-of-Life Care
- Providing an online meeting place for the Task Group on Volunteer Best Practices and Quality, with the support of Health Canada's Secretariat on Palliative and End-of-Life Care
- Working with Health Canada's Secretariat on Palliative and End-of-Life Care, Pallium, the Canadian Hospice and Palliative Care Association, and Educating Future Physicians in Palliative and End-of-Life Care, among others, to coordinate the availability of online palliative care resources for health care professionals

In looking to the future, the challenge for the Canadian Virtual Hospice is to ensure that the site provides information and support while closely meeting the needs of a diverse audience – not only patients and their friends and families, but also health care professionals, volunteers and researchers. Recently, the Canadian Virtual Hospice has conducted research examining opportunities to meet the needs of dying children, their families and friends, and children facing the death of a loved one.

The Canadian Virtual Hospice is continually working to make www.virtualhospice.ca more robust. And, if the job is done well, two emerging trends identified in distinct bodies of research mean that Canadians will make use of the service: first, people prefer to remain at home in the final stages of life, making the need for supplemental health information even more vital; and second, Internet use by health consumers is growing, making Canadians more likely to seek out that supplemental health information online. These trends, taken with Canada's aging population, mean that the Canadian Virtual Hospice can be expected to perform an increasingly important support role for Canadians in the years ahead.



www.virtualhospice.ca

Financial Statements

NOTICE TO READER

I have compiled the statement of financial position of Canadian Virtual Hospice as at March 31, 2006 and the statement of operations for the year then ended from information provided by management. I have not audited, reviewed or otherwise attempted to verify the accuracy or completeness of such information. Readers are cautioned that these statements may not be appropriate for their purposes.

Krahn - matthewson

Jeanne Krahn-Matthewson Chartered Accountant Winnipeg, Manitoba

August 29, 2006

CANADIAN VIRTUAL HOSPICE STATEMENT OF OPERATIONS FOR THE YEAR ENDED MARCH 31, (UNAUDITED - SEE NOTICE TO READER)

	2006	2005	2004	2003
Revenue				
Contributions				
Manitoba Health	\$ 282,687	\$ 150,737	\$ 90,366	\$-
Riverview Health Centre	771	76,297	7,273	80,823
Western Economic Diversification	-	64,354	154,259	270,578
Health Canada	-	-	9,999	-
Other	5,000	-	1,985	-
	288,458	291,388	263,882	351,401
Expenses				
Salaries and benefits	187,329	189,591	98,725	8,990
Marketing	68,673	20,366	29,661	442
Website costs	17,106	71,751	109,336	324,340
Administration expenses	10,200	5,526	4,867	1,814
Professional fees	2,001	3,072	18,651	10,000
Research	1,326	-	-	-
Travel	1,310	108	-	-
Committee costs	513	974	2,642	5,815
	288,458	291,388	263,882	351,401
Excess of revenues over expenses	\$ -	\$ -	\$-	\$ -

CANADIAN VIRTUAL HOSPICE STATEMENT OF FINANCIAL POSITION MARCH 31, (UNAUDITED - SEE NOTICE TO READER)

	2006	2005	2004	2003
Assets				
Current				
Advances	\$ 21,702	\$ 23,037	99,480	67,94
Prepaid expense	\$ 21,702	₽ Z3,037	99,480	2,04
	21,702	23,037	100,397	<u>2,04</u> 69,99
	21,702	25,057	100,597	09,95
Fixed assets				
Computer equipment	14,965	14,965	14,965	7,16
Accumulated amortization	(14,965)	(12,365)	(7,376)	(2,38
Net book value	-	2,600	7,589	4,77
		¢ 25.627	t 107.000	<i>*</i> - <i>*</i> - <i>*</i>
	\$ 21,702	\$ 25,637	\$ 107,986	\$ 74,76
iabilities				
Current				
Accounts payable and accrued liabilities	\$ -	\$ 565	\$-	\$ 2,46
Deferred contributions	21,702	22,472	100,397	67,53
	21,702	23,037	100,397	69,99
				
Net assets				
Investment in fixed assets	-	2,600	7,589	4,77
Unrestricted	-	-	-	
	-	2,600	7,589	4,77
	¢ 04.700		¢ 107.000	¢ 7474
	\$ 21,702	\$ 25,637	\$ 107,986	\$ 74,76

CANADIAN VIRTUAL HOSPICE NOTES TO THE FINANCIAL STATEMENTS MARCH 31, 2006 (UNAUDITED - SEE NOTICE TO READER)

1. Nature of operations

The Canadian Virtual Hospice is a national web-based initiative which provides bilingual information and support to palliative care patients, their families and friends, health care professionals and volunteers. Conceived in 2001, the web-site was officially launched in February 2004.

The Canadian Virtual Hospice operates, both administratively and financially, under the auspices of CancerCare Manitoba and the Winnipeg Regional Health Authority.

2. Significant accounting policies

The financial statements have been prepared in accordance with Canadian generally accepted accounting principles and reflect the following significant accounting policies :

a) Fixed assets

Fixed assets are recorded at cost. Amortization of fixed assets is computed using the straight-line method at rates calculated to amortize the cost of the assets less their residual values over their estimated useful lives. The following annual rates have been applied as follows:

Computer equipment 33%

b) Revenue recognition

Contributions are recognized when the recoverable costs are incurred as per the contribution agreements.

Contributions of supplies and services that would otherwise have been purchased are recorded at fair value at the date of the contribution.

- c) Deferred contributions
 Deferred contributions represent operating funding relating to expenses of future years.
- e) Use of estimates

The preparation of financial statements in conformity with Canadian generally accepted accounting principles requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosures of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenue and expenses during the reporting period. Actual results could differ from these estimates.

3. Economic dependence

Canadian Virtual Hospice derives a significant proportion of its contributions from Manitoba Health and Manitoba Energy Science and Technology. The following funding has been committed for the year ended March 31, 2007.

Manitoba Energy Science and Technology	\$ 331,000
Manitoba Health	306,263
	\$ 637,263

ACKNOWLEDGEMENTS

The Canadian Virtual Hospice gratefully acknowledges the contributions of our funding partners and extends our deepest thanks for their support and commitment to the project.

In the four-year period covered in this report, several organizations invested more than \$100,000 each to support the efforts of the Canadian Virtual Hospice, as shown below:



The Canadian Virtual Hospice is also grateful for the administrative and in-kind support received from CancerCare Manitoba and the Winnipeg Regional Health Authority.

Finally, the Canadian Virtual Hospice is indebted to Senator Sharon Carstairs for her leadership in palliative care and her invaluable assistance in the establishment of www.virtualhospice.ca.

CANADIAN VIRTUAL HOSPICE TEAM MEMBERS (2002/03 - 2005/06)

Management Committee Dr. Harvey Max Chochinov, Chair Anita Stern, former Co-Chair Josette Bérard, Executive Director Dr. Mike Harlos, Physician Consultant Lorena McManus, WRHA Liaison/Representative

Clinical Nurse Specialists Alexandra Beel Brenda Peters-Watral Simone Stenekes Suzanne Wowchuk

Physician Consultants Dr. Garnet Crawford Dr. Joshua Shadd

The Virtual Hospice has been



CANADIAN VIRTUAL HOSPICE NATIONAL ADVISORY COMMITTEE

Harvey Max Chochinov, OM, FRSC Canadian Virtual Hospice Chair Canada Research Chair in Palliative Care Professor, Dept. of Psychiatry and Family Medicine (Division of Palliative Care), University of Manitoba Director, Manitoba Palliative Care Research Unit CancerCare Manitoba

Anita Stern, MScN, PhD (candidate) Former Canadian Virtual Hospice Co-Chair (term: 2001-2006) Associate Investigator, System-linked Research Unit McMaster University Hamilton, Ontario

Josette Bérard, BA, MPA Executive Director, Canadian Virtual Hospice Winnipeg, Manitoba

G. Michael Downing, MD Medical Director, Victoria Hospice Society Clinical Assistant Professor, UBC Faculty of Medicine, Dept. of Family Practice Division of Palliative Care Palliative Medicine Consultant, BC Cancer Agency President, Canadian Society of Palliative Care Physicians Adjunct Assistant Professor, UVic School of Health Information Sciences

Serge Dumont, PhD Professeur, École de service social Pavillon Charles De-Koninck Université Laval Québec

Konrad Fassbender, PhD Senior Research Associate, Division of Palliative Medicine Alberta Cancer Board Palliative Care Research Initiative Grey Nuns Community Hospital Edmonton, Alberta Gerri Frager RN, MD, FRCPC (term: 2001-2006) Medical Director Pediatric Palliative Care Service, IWK Health Centre Assistant Professor Dalhousie University Halifax, Nova Scotia Faculty Scholar Alumnus, OSI's Project Death in America

Pierre R. Gagnon, MD, FRCPC Psychiatre specialise en psycho-oncologie L'Hôtel-Dieu de Québec (Centre hospitalier universitaire de Québec) et Maison Michel Sarrazin Professeur adjoint, Faculté de Pharmacie, Université Laval Quebec, Quebec

Romayne Gallagher, MD, CCFP (term: 2001-2005) Director, Division of Palliative Care, University of British Columbia Clinical Professor, Department of Family Practice

Mike Harlos, MD, CCFP, FCFP Medical Director, Palliative Care Program Winnipeg Regional Health Authority Medical Director, St. Boniface Hospital Palliative Care Section Head, Palliative Care, Dept. of Family Medicine Professor, University of Manitoba, Faculty of Medicine

Alejandro (Alex) R. Jadad, MD, DPhil, FRCPC Rose Family Chair in Supportive Care Canada Research Chair in eHealth Innovation Chief Innovator and Founder, Centre for Global eHealth Innovation Professor, Depts. of Health Policy, Management and Evaluation, and Anesthesia University Health Network and University of Toronto S. Lawrence Librach, MD, CCFP, FCFP Vice President, Canadian Hospice Palliative Care Association Physician Leader, EFPPEC Project Director: The Temmy Latner Center for Palliative Care Professor, Dept. of Family and Community Medicine, University of Toronto W. Gifford-Jones Professor, Pain Control and Palliative Care, University of Toronto

Jay Lynch, RN, BAdm, MEd Clinical Telehealth Program Coordinator The Ottawa Hospital Ottawa, Ontario

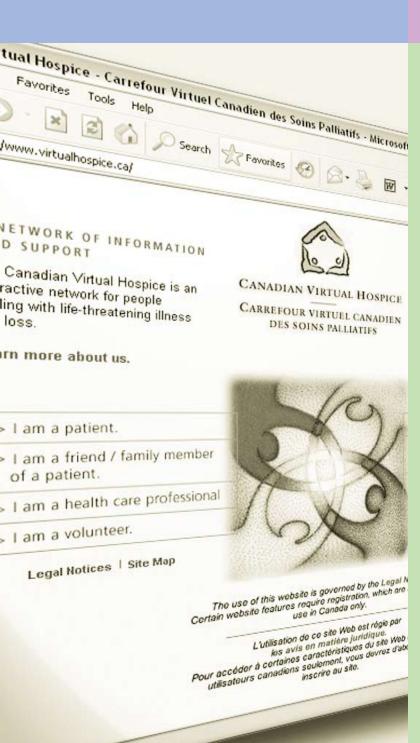
Lorena McManus, RN, BN, MPA Program Director Palliative Care Program Winnipeg Regional Health Authority Winnipeg, Manitoba

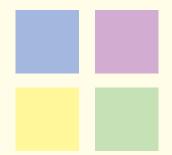
Jose Luis Pereira, MBChB, DA, CCFP (term: 2001-2005) Medical Director, Tertiary Palliative Care Unit Calgary Medical Region Foothills Medical Centre Calgary, Alberta

Patty A. McQuinn, RN, BSc, MScN (Applied) Palliative Clinical Nurse Specialist South-East Regional Health Authority Moncton, New Brunswick

Robin Weir, RN, PhD (term: 2001-2005) Investigator, Community Linked Evaluation Aids Research Unit (C.L.E.A.R.) Associate Investigator, System-Linked Research Unit Professor Emeritus, School of Nursing, McMaster University Hamilton, Ontario Director, Research Institute, Bridgepoint Health, Toronto, Ontario









CANADIAN VIRTUAL HOSPICE

CARREFOUR VIRTUEL CANADIEN DES SOINS PALLIATIFS

> www.virtualhospice.ca www.carrefourpalliatif.ca

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Cette information est disponible en français