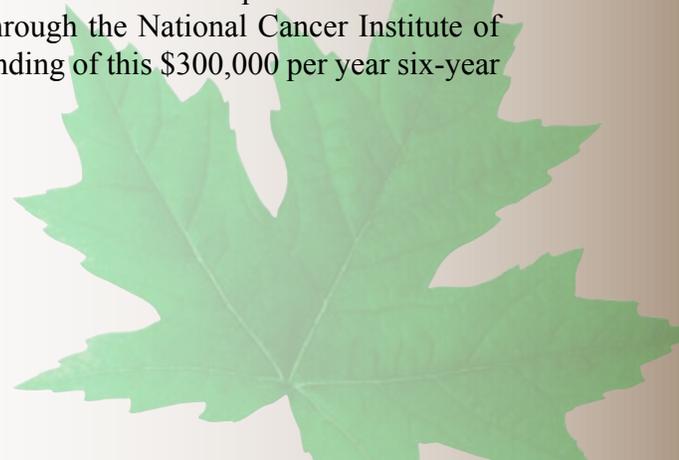


## Palliative and End-of-Life Care

The term palliative care refers not only to the care and management of patients approaching the end of life but also addresses the reduction of suffering throughout the course of illness and, for family, into bereavement. Palliative and end-of-life care, although traditionally associated with cancer care, intersects with a number of other clinical disciplines, such as cardiology, respiratory medicine, critical care, nephrology, pediatrics and neurology. As our aging population continues to grow and modern medicine provides the means to prolong the life of individuals with a variety of life-limiting diseases and conditions, society struggles with the ethical and legal questions around “appropriate” use of health care resources. Quality of care toward and at the end of life is also a significant issue. Many of the people who could benefit from palliative and end-of-life care do not receive it. All too often it is left to patients, their families and a loosely knit community of volunteer organizations to sort through the myriad of physical, psychological, spiritual and ethical choices.

The key to change lies in rigorous scientific research that will provide the evidence for informed decision making by clinical practitioners and policy makers. Historically, palliative and end-of-life care research has been underfunded in Canada and small groups of highly committed and dedicated researchers have struggled to obtain recognition for the field as an independent health discipline.

Palliative and end-of-life care was identified by the CIHR Institute of Cancer Research (ICR) as one of its six original strategic research priorities in 2002. As a first step, ICR immediately took advantage of the opportunity to partner on two programs already approved for CIHR funding. The first was a New Emerging Team (NET) project led by Dr. Pierre Allard, from the University of Ottawa that focused on the structure, process, quality and outcomes of end-of-life care for older persons and how personal, social and environmental factors affect care. This \$300,000 per year five-year project, submitted in response to a Request for Applications (RFA) launched by the CIHR Institute of Aging (IA), was jointly funded by ICR and IA. The second was a CIHR Strategic Training Program grant led by Dr. Robin Cohen of McGill University designed to give students and new researchers exposure to all aspects of palliative and end-of-life care and train them to transfer their results quickly to the clinicians who work as front line contacts in palliative care. ICR and the Canadian Cancer Society (CCS), through the National Cancer Institute of Canada (NCIC), partnered equally on the funding of this \$300,000 per year six-year program.



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## Palliative and End-of-Life Care Initiative

In June 2003, CIHR and partners launched a palliative and end-of-life care initiative that reflected the multiple needs of the palliative care research community. The initiative was designed to support infrastructure development, enhance interdisciplinary research collaboration, encourage the development of early career researchers and attract trainees to this emerging area. This multidisciplinary initiative supported nineteen Pilot Projects, nine New Emerging Team Grants, and one Career Transition Award. This initiative along with the previously funded NET and Strategic Training Program represents a total investment of \$16.5 million over six years into palliative and end-of-life care research, the largest research investment in this field ever made in Canada.

This extraordinary investment was made possible by the contributions of many partners. The support of the provincial cancer boards and agencies made it possible to fund research teams across the country, forming the basis of a national network in palliative and end-of-life care research.

## Partners Supporting Palliative and End-of-Life Care Research

Alberta Cancer Board  
British Columbia Cancer Agency  
Canadian Breast Cancer Research Alliance  
Cancer Care Manitoba  
CIHR Institute of Aboriginal Peoples' Health (IAPH)  
CIHR Institute of Aging (IA)  
CIHR Institute of Cancer Research (ICR)  
CIHR Institute of Circulator and Respiratory Health (ICRH)  
CIHR Institute of Gender and Health (IGH)  
CIHR Institute of Health Services and Policy Research (IHSPR)  
CIHR Institute of Human Development, Child and Youth Health (IHDCYH)  
CIHR Institute of Neurosciences, Mental Health and Addiction (INMHA)  
CIHR Knowledge Translation Branch  
Health Canada  
Heart and Stroke Foundation of Canada  
National Cancer Institute of Canada  
National Ovarian Cancer Association

ICR continued to invest in this strategic priority area through the CIHR Institute of Gender and Health-led Reducing Health Disparities & Promoting Equity for Vulnerable Populations Interdisciplinary Capacity Enhancement (ICE) grants. McMaster University's Dr. Allison Williams and Dr. Donna Wilson received funding for an ICE grant entitled "*Timely access & seamless transitions in rural palliative/end-of-life care*". This grant focuses on timely access to palliative care in rural communities, encompassing two of ICR's major priority areas (Palliative and End-of-Life Care and Access to Quality Cancer Care).

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## Results and Outcomes

### Palliative and End-of-Life Care: Pilot Projects

Nineteen one-year Pilot Project grants, designed to target and assess innovative approaches in implementing palliative and end-of-life care, were funded. The purpose of these grants was to target and assess innovative approaches in implementing palliative and end-of-life care. Nineteen pilot projects were funded from across the country. The pilot projects examined a wide range of research topics including end-of-life quality indicators in lung cancer; end-of-life health care costs; pediatric palliative care surveillance; and palliative care service utilization.

Principal Investigator	Institution Name	Project Title
Alibhai, Shabbir	University Health Network	A pilot study to evaluate quality of life in patients age 60 or older with newly diagnosed acute myeloid leukaemia.
Aubin, Michèle	Université Laval	Évaluation d'un programme de soulagement de la douleur chez les personnes âgées en perte grave d'autonomie vivant en milieu de soins de longue durée : projet pilote.
Baracos, Vickie	University of Alberta	Nutritional supportive care: amino acids required to support maintenance and deposition of lean body mass in patients with advanced cancer.
Barbera, Lisa	Sunnybrook and Women's College Health Sciences	Palliative and end-of-life quality indicators in lung cancer.
Duggleby, Wendy	University of Saskatchewan	A pilot study of the hope focused program for informal caregivers of palliative home care patients.
Fassbender, Konrad	Alberta Cancer Board	Patterns and predictors of palliative care service utilization.
Gagnon, Bruno	McGill University	Characterizing cognitive failure, physical retardation and hypo-active delirium in advanced cancer patients, a pilot project.
Grunfeld, Eva	Dalhousie University	Quality indicators for end-of-life breast cancer care: is there agreement between stakeholder groups in two provinces?
Grunfeld, Eva	Dalhousie University	Quality indicators for end-of life breast cancer care: testing the use of administrative databases in two provinces.
Hampton, Mary	University of Regina	Developing and piloting cross-cultural curriculum for delivery and utilization of end of life health care services.
Kiceniuk, Deborah	Dalhousie University	An examination of end-of-life health care costs in Nova Scotia.

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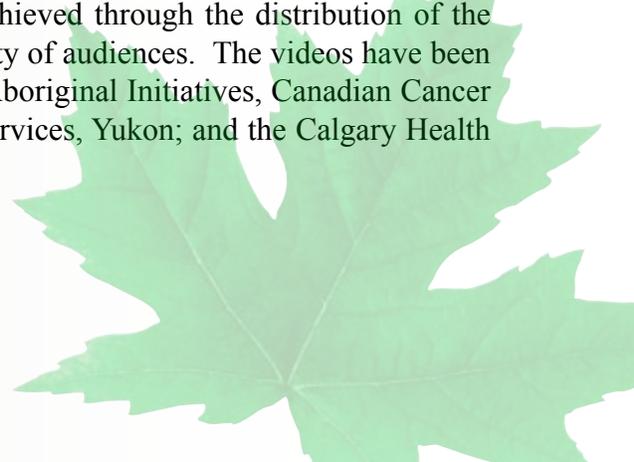
Leis, Anne	University of Saskatchewan	Prevalence of palliative patients and their health services utilization in Saskatchewan: A feasibility study.
Schondorf, Ronald	Sir Mortimer B. Davis Jewish General Hospital	Does autonomic nervous system dysfunction contribute to the morbidity of patients with advanced gastrointestinal and non small cell lung cancer? A pilot study.
Simpson, John Steven	University of Calgary	A pilot project to assess the impact of a novel psychosocial intervention on the quality of life, attitudes to death and dying, and spirituality of palliative cancer patients.
Vigano, Antonio	McGill University	Prognostic value of the angiotensin-converting enzyme gene polymorphism in advanced cancer: A pilot study.
Viola, Raymond	Queen's University	Community palliative cancer care - A pilot study using linked databases.
Ward-Griffin, Mary	University of Western Ontario	Exploring client-family-nurse relationships in home-based palliative care for seniors.
Widger, Kimberley	IWK Health Centre	Pediatric palliative care surveillance pilot project.
Wing, Simon	McGill University	Role of lysosomal proteolysis in mediating the muscle wasting of cachexia.

The following highlights a small selection of the outcomes from the 19 funded pilot projects.

*“Developing and piloting cross-cultural curriculum for delivery and utilization of end-of-life health care services” – Dr. Mary Hampton, University of Regina*



Dr. Hampton's pilot project examined the underutilization of palliative care services by Canadian Aboriginal communities. Using Community Action Research methodology Dr. Hampton's team created two videos to address the following objectives (1) inform end of life health care providers of culturally sensitive protocol when dealing with Aboriginal families; (2) inform the community of end-of-life care services (increase awareness); and (3) increase Aboriginal families' use of these services. Dissemination of the results of the pilot project has been achieved through the distribution of the two videos and the presentation of the research findings to a variety of audiences. The videos have been sold on a cost recovery basis to health care providers, including Aboriginal Initiatives, Canadian Cancer Society, Manitoba; Palliative Care Program, Health and Social Services, Yukon; and the Calgary Health Region's Regional Palliative and Hospice Care Service.



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*“A pilot study to evaluate quality of life in patients age 60 or older with newly diagnosed acute myeloid leukemia” – Dr. Shabbir M. H. Alibhai, University Health Network*



Dr. Alibhai’s pilot project examined the quality of life and fatigue in individuals age 60 and over who had recently been diagnosed with acute myeloid leukemia (AML). Prior to the study, little was known about the impact of intensive chemotherapy on patient’s quality of life. The pilot project found that intensive chemotherapy was associated with similar or better quality of life than less aggressive treatment approaches or supportive care. Following the conclusion of the pilot project, Dr. Alibhai has received multi-year funding from CIHR to conduct a larger study looking at quality of life and fatigue in older and younger people with AML.

*“A pilot study of the hope focused program for informal caregivers of palliative home care patients” – Dr. Wendy Duggleby, University of Saskatchewan*



Dr. Duggleby presented the results of the pilot project on the family caregiving experience and the development of a hope intervention for these caregivers at a local workshop for the Council of Aging. This presentation resulted in media coverage for the study’s outcomes, the opportunity to share the findings with a Member of Parliament, Carol Skelton, and fostered a new and active collaboration between Dr. Duggleby and a community based decision making body, the Council of Aging.

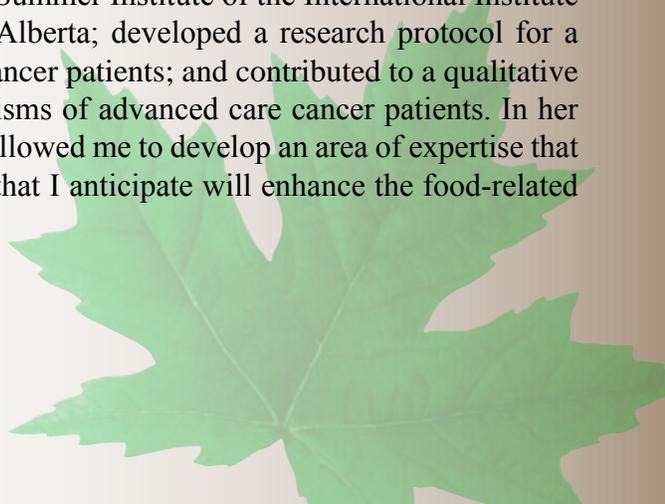
## **Palliative and End-of-Life Care: Career Transition Awards**

The goal of the Career Transition Awards was to provide support to researchers to enable them to shift their research focus within palliative care or to transition to the field from another discipline. One, six month award was supported through the initiative.

Principal Investigator	Institution Name	Project Title
Wismer, Wendy	University of Alberta	Dietary patterns, perceptions of food and motivation to eat in palliative care cancer patients.



Dr. Wendy Wismer from the University of Alberta used her award to learn about the theory of qualitative research and apply it to research in a food and cancer setting. During the tenure of her award, Dr. Wismer attended the Summer Institute of the International Institute of Qualitative Methods at the University of Alberta; developed a research protocol for a study regarding food selection by advanced cancer patients; and contributed to a qualitative publication on the nutritional coping mechanisms of advanced care cancer patients. In her own words: “The career transition award has allowed me to develop an area of expertise that is unique and personally rewarding, and one that I anticipate will enhance the food-related quality of life for those in end of life care.”



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## Palliative and End-of-Life Care: New Emerging Teams

The New Emerging Team (NET) grants component of the Palliative and End-of-Life Care initiative was designed to build capacity and to promote the formation of new research teams or the growth of small existing teams. Nine NET grants were supported through this initiative, in addition to Dr. Pierre Allard's NET. The five year grants began in 2004 and will be completed in 2009. Research supported through the NETs cover a wide range of research topics such as family caregiving, cancer-associated cachexia and anorexia, vulnerable populations, and improving communication and decision-making.

Principal Investigator	Institution Name	Project Title
Allard, Pierre	Elizabeth Bruyère Research Institute, Ottawa	Optimizing end-of-life care for seniors.
Baracos, Vickie	University of Alberta	New Emerging Teams in palliative care: Cancer-associated cachexia-anorexia syndrome.
Chochinov, Harvey; Stienstra, Deborah	University of Manitoba	End-of-life care and vulnerable populations.
Doll, Richard; Kazanjian, Arminée	British Columbia Cancer Agency	Palliative care in cross-cultural context: A NET for equitable and quality cancer care for ethnically diverse populations.
Gagnon, Pierre	Université Laval	Developing, evaluating and implementing new interventions in palliative care.
Hagen, Neil; Fainsinger, Robin; Brasher, Penelope	University of Calgary	A multidisciplinary cancer pain research network to improve the classification, assessment, and management of difficult cancer pain problems.
Heyland, Daren	Kingston General Hospital	Understanding and improving communication and decision-making at the end-of-life.
Kirk, Peter; Lau Francis	University of Victoria	Overcoming barriers to communication through end-of-life and palliative transitions.
Siden, Harold	University of British Columbia	Transitions in pediatric palliative and end-of-life care.
Stajduhar, Kelli; Cohen S. Robin	University of Victoria	Family caregiving in palliative and end-of-life care: A new emerging team.

Midway through the five year projects, the 10 NET grants collectively have over 180 publications and have made over 450 presentations. The following highlights a small selection of the mid-grant research outcomes, to date, from the ten funded NET grants.

# Canadian Institutes of Health Research (CIHR) Institute of Cancer Research (ICR)

*“A multidisciplinary cancer pain research network to improve the classification, assessment, and management of difficult cancer pain problems” – Dr. Neil Hagen, Robin Fainsinger and Dr. Penelope Brasher, University of Calgary*

As a component of their research grant, Drs. Hagen, Fainsinger, and Brasher’s team have conducted an exhaustive literature search focused on knowledge translation for techniques aimed to improve pain management. Preliminary results show that knowledge translation interventions that target health professionals to support improved cancer pain control often fall short of their intended effect and that similar interventions aimed at patients are more likely to work. These results may inform future planning of knowledge translation strategies in cancer pain control.

*“Family caregiving in palliative and end-of-life care: A new emerging team” – Dr. Kelli Stajduhar and Dr. Robin Cohen, University of Victoria*



One of the studies conducted by this NET examined the factors that influence a caregiver’s ability to cope while providing end-of-life care at home. Five factors were identified: (1) the caregiver’s approach to life; (2) the patient’s illness experience; (3) the patient’s recognition of the caregivers’ contribution to his or her care; (4) the quality of the relationship between the caregiver and the dying person; and (5) the caregiver’s sense of security. These findings may inform health services and policies directed at enhancing family caregivers’ coping abilities.



*“Overcoming barriers to communication through end-of-life and palliative transitions” – Dr. Peter Kirk and Dr. Francis Lau, University of Victoria*

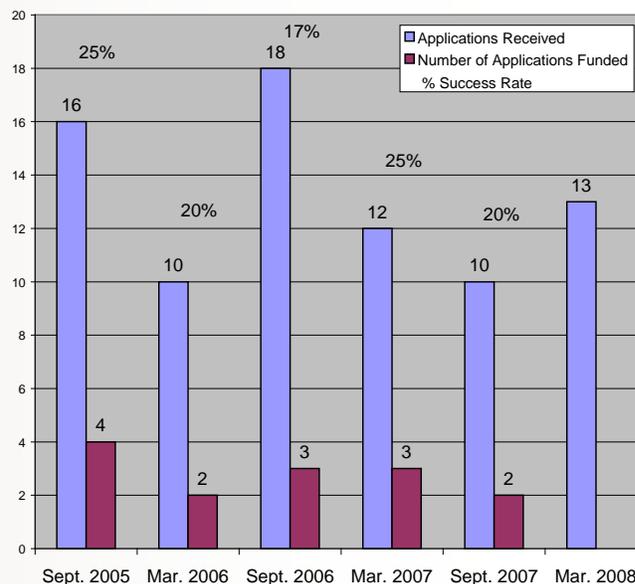
The extensive research of this NET, led by Dr. Kirk and Dr. Lau, on the Palliative Performance Scale (PPS) has contributed to the growing evidence base needed to support the policy and practice of palliative care in Canada. The PPS measures the functional status of a patient and assigns them a Palliative Performance Value. This value also serves as a communication tool for quickly describing a patient’s current functional level. As a result of their research, patients in British Columbia with a PPS of 50% (which indicated that the patient requires considerable assistance and is not able to do any work) or less are now eligible for enrolment in the Palliative Care Benefits Program which allows free prescriptions and other services for patients with a prognosis of less than six months.

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## Ensuring Sustainability

To support continued growth in palliative and end-of-life care research, and in response to a growing need within the research community, CIHR created a new peer review committee that will evaluate all operating grant applications within the area of palliative and end-of-life care. Previously, such applications were reviewed by a variety of different committees. It is anticipated that interest in palliative and end-of-life care research will continue to grow, and that the creation of a dedicated, multidisciplinary committee will better serve the needs of this growing scientific community. The committee also reviews proposals that address critical evaluation of ethical, legal, economic and moral issues pertaining to the utilization of health care resources and quality of care.

## Palliative and End of Life Care Peer Review Panel



## Evaluation

A full evaluation of ICR's commitment to palliative and end-of-life care research is planned following the completion of the New Emerging Team Grants. One of the primary objectives of the Palliative and End-of-Life Care initiative, however, was to increase research capacity in this area in response to an identified need. In 2001/2002 CIHR funded only 14 projects focused on palliative care for a total investment of \$629,928. In 2007/2008, 58 projects were funded for a total investment of \$5,854,997, almost a ten-fold funding increase. In addition, the ten Principal Investigators funded in 2001/2002 grew to 86 in 2007/2008, and the number of co-investigators went from 23 to 201 over the same period. These figures demonstrate a dramatic increase in research capacity over a six-year period, largely as a result of the sustained efforts and commitment of ICR and partners.

## Increased research capacity in the area of Palliative and End-of-Life Care

