What is PE: ace?

PE: ace stands for Palliative Enhancement: assessment, care and education representing the ‘Enhancing provision of Palliative Care by Physicians: integrating primary care and interdisciplinary specialist palliative care’ demonstration project funded through the Primary Health Care Transition Fund of the Ministry of Health and Long Term Care. This project, which aims to integrate primary care and interdisciplinary specialist palliative care, involves 20 family physicians from 3 family practice sites in the municipality of West Lincoln, Ontario. The project’s enhanced palliative care team works with physicians from the practice sites to improve and enhance the delivery of effective palliative care for patients at the end-of-life (EOL).

Palliative enhancement will occur by providing an EOL care program to patients and their families encompassing 24 hours a day, 7 days per week access to palliative care consultants and interdisciplinary supportive patient care including a trained physician practice leader from each of the group practices.

Assessment will include quantitative and qualitative measurement to evaluate participants’ experience of how well EOL care needs were addressed, reduction in patient and family symptom severity and distress, timeliness of referral and access to palliative interdisciplinary care services, family doctor knowledge of comfort with provision of palliative care, reduction in emergency visits and numbers of hospital deaths, and preferences for EOL treatment and location of death.

Care provision includes a holistic approach to the management of mental, physical, emotional, and psycho-spiritual symptoms and issues faced by patients at the end-of-life (EOL). Care aims are to improve the overall standard and quality of care delivered to patients and their families by improving access to resources thereby reducing the severity and distress associated with EOL symptoms, and to provide patients with appropriate pharmacotherapy.

Education of family physicians and development of a shared care clinical and educational model will play a critical role in improvement to the quality of EOL care. Based on expressed physician preference, this individualized, integrated model of care aims to build primary physician palliative care knowledge and expertise to address gaps in service.
“The need to reform the primary health care system’s delivery of effective palliative care is urgent since the demand for palliative care will increase with an aging population and a rising prevalence of cancer”
Denise Marshall

Meet the EPC team- PE: ace Makers

The project includes two groups; a multi-disciplinary group of practitioners whose focus is enhanced end-of-life (EOL) physical, mental, emotional, psychological and spiritual care of patients and their families, and a steering committee of researchers that aims to further educate primary care doctors in palliative care and to broaden research knowledge in EOL care.

The ‘enhanced palliative care team’ (EPCT), building on the novel work of the West Lincoln Palliative Care Team (WLPCT), provides enhanced services 24 hours per day, 7 days per week. The EPCT, working in collaboration with the WLPCT and family doctors from the 3 practice sites in Beamsville, Grimsby and Smithville, meet weekly to discuss patient intake process, patient and family symptom issues and their management. The EPCT is composed of a palliative care physician, an advanced practice nurse, a Community Care Access Centre (CCAC)-Niagara case manager, a bereavement support person, a psycho-spiritual counselor, and a St. Elizabeth’s Health Care nurse representative.

At least once in our lives we ‘name drop’; that is we gain implicit access where access might otherwise be denied by mentioning a well-known person’s name. Such is the case with mentioning the name Dr. Denise Marshall to family physicians, patients and their caregivers, pharmacists, printers or other community members in the Niagara/West Lincoln regions of Ontario. This is due to Denise’s passionate social activism in domestic violence, early childhood development, and community development like public lobbying for the existence of small schools and rural hospitals. For such activities, she was awarded ‘Citizen of the Year’ in 2002 by the town of Grimsby, and ‘Queen Golden Jubilee Medal’ winner in 2004. Educated at McMaster University, Denise has primarily focused her educational, professional and scholarly activities in palliative care. While space limits the complete list of her administrative roles in health care in Hamilton and West Lincoln, she is medical director of the WLPCT which she founded in 1997, and is the inaugural Director of the Division of Palliative Care, Department of Family Medicine. She also was honored for her leadership and teaching in palliative care since 1998 with the 2003 John C Sibley award. Denise’s energy, warmth, sense of humor and dedication displayed in these roles is truly inspiring considering she balances it all with the roles of wife and mother to 3 children.

In addition to having a strong pilot or leader of the PE: ace maker team, it was necessary to find someone to effectively navigate the myriad of complex issues and care-provider relationships of patients at the end-of-life. That navigator was found with the addition of Kathleen Willison, as the Advanced Practice Nurse Navigator (APPN) to the EPCT. Using her specialized education and practice skills in palliative care, Kathleen is the point of contact between patients and their families, family doctor and community service providers to ensure timely access to services and solutions. This includes patient/caregiver assessment, liaising with the practice sites, being on call, development of educational and assessment tools for the project...in other words...the one who interprets all the ‘maps’ of the project. For the length of the project, Kathleen is on loan from her other roles as a Clinical Educator/Researcher with VON Hamilton, and Clinical Nurse Specialist with the Palliative Care Team of St. Joseph’s Healthcare, Hamilton, and whether they know it or not, from her husband and 3 sons!

Do you sense a theme yet about these women?
Janet Devine is the Bereavement Support person with the EPCT. Janet obtained certification in Palliative Care from Niagara College, and will graduate this spring from King’s College at Western where she completed grief and bereavement studies. Janet has balanced her 8 years of work in bereavement support with a passion for gardening, on both a volunteer and personal level. Understandably, this passion has provided a great foundation for Janet in addressing the life cycle issues faced by family members of project clients, and informs her role in the EOL care process. Janet describes that she is enjoying her work in West Lincoln on the project, and is able to work so effectively due to the ‘gardener’ in her life, her husband. The EPCT has also appreciated Janet’s co-chairing with Kathleen of team rounds which start with an inspirational message, and finish on time...her ‘green thumb’ at work even in this task!

It’s easy to see from her picture why Paola Lawrence is perfectly suited to case management for CCAC-Niagara and to be a member of the EPC team. While her warmth, openness, attention and sense of humor are quite evident, even more importantly, to get an accurate assessment of clients’ issues she has the resources readily available; her valuable journal and pen for recording and reporting, her resource folders, and water to fuel herself while juggling these multi-tasks. These organizational skills have been honed and developed during 11 years with Home Care/CCAC in the Niagara region. She also married and had 2 children during this period. Paola, representing the CCAC-Niagara Supportive Care Team, was an original 1997 member of the West Lincoln Palliative Care Team whose work provided foundation for this project, so she has the enthusiasm to her work.

Remember name O’Connor, it was clear at equally as important as a spiritual counselor’ she person. She is now the warmer, more accessible description of the emotional, psychological and spiritual support Maureen provides to EPCT clients and their families. She truly understands support, as evidenced by her previous work and educational activities, particularly in the formation of Wellwood Resource Centre of Hamilton with her husband, oncologist Greg O’Connell, who lived with and died from cancer. Maureen’s testimony of her client interactions says it all: “Since joining the EPCT in January I have been busy working with patients & family members finalizing wills & POAs, funeral arrangements, planning a wedding, shoveling snow, collecting eggs...providing support & information on caring for loved ones at the end-of-life & accompanying them as they search for meaning & spiritual solace”.

Last, but definitely not least, the EPCT is supported by the palliative care nurses with St. Elizabeth’s Health Care (SEHC). These home visiting nurses, who provide input to the team at rounds on a rotating basis, are one of the vital links between patients and their family doctors and Kathleen, the APN navigator, in the continuity of care that ensures timely access to needed treatment to address patients’ EOL care needs. On a daily basis, they work hard, long and tireless hours, clearly demonstrating the professionalism, patience, and perseverance needed to support patients and their families in their choice of where they wish to be at the end-of-life, home.
Meet the Research Team:

Having been introduced to Denise & Kathleen, please meet the project’s research team members:

**Doris Howell, RN, PhD. Co-Principal Investigator:** Dr. Doris Howell’s current research focus is on clinical quality care indicators for end-of-life care and the evaluation of health care systems and care delivery models on patient/family health care system and cost outcomes. Doris has a combination of quantitative and qualitative methodology skills including linkage of administrative databases and has a strong clinical and consulting background in cancer and palliative care. She has acted as Principal Investigator and Co-investigator on a number of research projects and interdisciplinary evaluation teams. A recent focus of her research has been on the evaluation of palliative home care delivery models on patient and family outcomes. Dr. Howell’s dissertation research focused on Predictors of Home Care Utilization and Place of Death for Cancer Patients Enrolled in an Integrated, Interdisciplinary Palliative Home Care Program.

**Alan Taniguchi, MD, CCFP, FCFP, ABHPM, Co-investigator:** Dr. Taniguchi has over ten years’ experience as a physician providing palliative care to individuals and their families in multiple settings in the continuum of care including community family practice, long term care, complex continuing care, and the acute care hospital. He was a founding member of the Hamilton palliative care community team, providing consultation and support to home-based clients. This clinical background, in addition to his practice as a community family physician, positions Dr. Taniguchi to expertly advise on the development, implementation, and evaluation of the project. His input is complemented by his administrative experience in program development as medical director of an in-patient palliative care program and by his extensive educational experience through a number of projects geared towards family physicians, such as the Ontario College of Family Physicians’ physician education initiative on dementia. Dr. Taniguchi has published a systematic review on the effectiveness of palliative care delivery systems and is a co-investigator in primary research examining the quality of care of the dying in the long-term care sector.

**Michelle Howard, MSc (PhD Candidate), Co-investigator:** Ms. Howard has seven years experience in developing, coordinating, and completing all aspects of research studies in primary care. Her experience relating specifically to this project includes implementing and coordinating a large primary care community-based trial using sampling, recruitment, and analytic methods similar to those proposed in the current project. In addition, she has published methodological papers on these issues in a peer-reviewed journal. She also has experience in data collection techniques for health service utilization by working closely with health economists and program evaluators. She has formal training in epidemiological methods at the Master’s and PhD level.

**Janusz Kaczorowski, PhD, Co-Investigator:** Dr. Kaczorowski has over 15 years experience in developing, coordinating, and completing all aspects of research studies in primary care. He acted as a consultant for the evaluation of primary care demonstration project in British Columbia. He is a sociologist with research background in family medicine, psychology, sociology, and epidemiology. He has had several large grants both as principal investigator and co-investigator and has published over 60 peer-reviewed articles. In 2000, he obtained CIHR/SSHRC/NHRDP new investigator health career award focusing on the implementation of evidence-based medicine and clinical practice guidelines in primary care settings. His role will be to assist with the study implementation and evaluation, problemsolve, monitor data collection, oversee data analysis, and draft reports and manuscripts.

**Kevin Brazil, PhD, Co-Investigator:** Dr. Brazil is well funded and published in the areas of health care of the older adult, EOL care, program evaluation, health services research, EBP in long term care, and organizational change. He will assist with study implementation and evaluation, intervention and research design issues, analysis, interpretation, writing of reports and manuscripts, and linkages and exchange with stakeholders.

**Lorraine Hoult, BA, BSW (in progress), Project Manager:** Ms. Lorraine Hoult comes to Palliative Care from 23 years working in the Department of Pediatrics as a Research Coordinator, Psychometrist and Data Manager in Neonatal Follow-up. She has been part of a large well published multi-disciplinary team involved in a longitudinal study involving 179 Extremely Low Birth weight infants and 145 matched controls. Her interest in Palliative Care has been developed over the years when interacting with families of dying infants in the neonatal unit and the personal life experience of losing her youngest son to cancer in 2001. It is her hope to become familiar with the issues in Palliative Care and eventually obtain a MSW to work in Pediatric Palliative Care. She is pleased to be part of the team and relishes the opportunity to learn as much as she can over the next 18 months.

**Diane Gauthier, Administrative Coordinator:** Ms. Diane Gauthier brings many years of administrative experience to the project, and of particular note was editor of Cochrane News for the CCNC. She is administrative coordinator for the Palliative Care Division of the Department of Family Medicine, and for the project provides administration support to Dr. Marshall particularly regarding the research team meetings.

**Bonnie Rush, Certificate Religious Studies, Project Assistant:** Bonnie has come full circle on this project since 20 years ago her first full-time research coordinator position was with the Department of Family Medicine. Since that time, Bonnie coordinated over 17 clinical research trials including a community-based trial for women with breast cancer, and a large scale research development project in geriatrics focused on competency which was one of 3 projects funded in 1994 by MHLTC and Ministry of the Attorney General. The EPC project is a good fit with her interest in promoting patient autonomy and advocacy. Bonnie was writer and editor of this the first edition of PE:ace News, and claims all errors and/or omissions as her own! Please direct any comments, queries or helpful suggestions to rushb@mcmaster.ca.