Quality Palliative Care in Long Term Care
A Community-University Research Alliance

Long-Term Care Homes: Hospices of the Future

Submission to the Canadian Nursing Association Expert Commission

Presented by the QPC-LTC Alliance

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Introduction

Palliative care is a philosophy and a specialized set of care processes that encompasses the physical, emotional, social, psychological, spiritual and financial needs of residents of long term care facilities and their families. Therefore, Palliative Care aims to enhance quality of life at the end-of-life in order to provide a "good death" when death is inevitable. While, LTC homes have become a major location of death in Canada, most do not have formalized Palliative Care programs.

In Ontario, almost 50% of the residents who live in LTC homes die each year. This means approximately four deaths per month for a home with 110 residents. Without a doubt, LTC homes are now in the "business of caring for people who are dying." The majority of residents who die in LTC have Alzheimer's disease or related dementias in conjunctions with several other chronic and terminal illnesses.

The new LTC Act in Ontario has recognized this new reality by mandating the provision of palliative care education for all staff providing direct care to residents in LTC homes. The Quality Palliative Care in Long Term Care (QPC-LTC) is working on creating a "tool kit" of best practices for long term care homes to develop formal palliative care programs. Please refer to Appendix A for Project Background.

The nurse to resident ratio is low in LTC compared to other settings that provide end of life care. Providing quality nursing care to residents is difficult as they have multiple and complex chronic and terminal illnesses that must be managed. Thus, it is important that the Canadian Nurses Association (CNA) advocate supporting all nurses working in LTC homes.

The Alliance recognizes that many of the principles of the CNA's political agenda are compatible with a position statement regarding Providing Nursing Care at The End of Life (2008) and the Hospice Palliative Care Nursing Certification (2009) with specialty competencies for registered nurses. **The Alliance asks that the expert commission consider the uniqueness of providing palliative care in long term care homes by reviewing the recommendations listed in the following brief.**

This brief is based on data from the Quality Palliative Care in Long Term Care research project. For more information regarding this project please visit our website at www.palliativealliance.ca. The recommendations are separated into three categories which include: education and professional development, funding, and regulations. A summary table of the project recommendation can be found in Appendix B.

Human Resources,

The CNA policy brief *The Long-term Care Environment: Improving Outcomes Through Staffing Decisions* (2008) highlights lack of staff or the right mix of regulated and unregulated providers to provide quality and quantity of care, lack of sufficient funding and inadequate staff education. The QPC-LTC data indicate that LTC home staff lacks knowledge, skills, and confidence in providing P/EOL care. While nursing staff are highly motivated to provide care at the EOL, they identified the need for more education, more assistance from volunteers and consultants, better communication and improved team work. Nursing staff expressed the feeling that their important contribution to P/EOL care was not recognized. In response to these issues our project has worked to build external community linkages that enhance existing human resources, provide grief support for staff, promote education about palliative end-of-life care, and promote empowerment of PSWs and their role in the interprofessional care team,.

Education and Professional Development

Building External Linkages

All staff reported a lack of human resources and a shortage of time to provide enhanced care at the EOL. Building linkages with community organizations is one way to supplement LTC staff as well as creating more time and specialized knowledge and skills in the homes. Many community organizations have a mandate to provide services in LTC, but the homes do not always engage these services. In our project, some key organizations that proved beneficial for LTC homes included: Pain and Symptom Management Consultants, Alzheimer Societies, multicultural and multifaith groups and hospices / hospice volunteer groups. Local Hospice Units can provide significant assistance by providing 24-hour consultations, referring staff to community experts, and written resources (e.g. books, brochures, directories), and can provide education and mentoring to LTC staff. Nurse Led Outreach Teams can provide assistance to staff when residents are transitioning towards P/EOL goals of care and support staff to provide EOL care. They help prevent unnecessary transfers to hospital at EOL. If the resident is transferred to hospital, the Nursed Led Outreach team can ensure smooth transitions during this period by sharing information with both the hospital and the LTC home. Pain management is an important component of P/EOL care and was outlined in the new LTC Act as one of the four mandatory programs that LTC homes must provide. Currently LTC homes have access to Pain and Symptom Management Consultants however these consultants are responsible for large geographical areas and several organizations. Providing LTC homes with dedicated Pain and Symptom Management Consultants would enhance LTC staff education and better manage resident pain.

Increase Palliative and EOL Care Education within College and University Programs

Nursing staff, both regulated and unregulated, felt unprepared to provide P/EOL care after basic education from a college or university program. They stated they had little to no P/EOL content within the curriculum. The staff commonly said they learned to provide PC through on-the-job experience caring for the dying. Also, to the knowledge of the Alliance there are no competencies for PCWs in PC and EOL care. The Alliance is working towards identifying educational competencies for PCWs providing PC. We are also advocating for these competencies to be included in PCW curriculum in the Ontario colleges. This will increase role clarity for other members of the interprofessional team including the registered nursing staff. The Alliance would also like to highlight the importance of targeting health care providers who are motivated to provide palliative care and encourage them to consider working in LTC homes as traditionally LTC has not been an attractive please for health care professionals to practice.

Provide Continuing Education Opportunities for Staff Working in LTC Homes

LTC staff indicated that there are few ways to receive education in palliative care. Currently one of the most effective ways they learn about PC /EOL care is through mentoring by other staff. The Alliance has used a variety of continuing education methods with the LTC staff including: arranging for LTC staff to shadow nursing staff from local hospices, encouraging LTC staff to receive the Palliative Care for Front Line Workers training developed by the Centre for Education and Research on Aging & Health (CERAH) at Lakehead University, and connecting staff with community organizations that have relevant expertise. Technology has been used to increase opportunities for nursing staff to receive palliative care continuing education. Some examples include using high fidelity simulation labs to give staff opportunities to practice having EOL conversations with residents and families and using the Ontario Telemedicine Network (OTN) to provide staff with access to education from other areas of the province.

Grief Support for Staff

One PCW participating in the project stated: “it’s hard to watch people die for a living.” This is a common feeling among the staff. Staff members become very attached to the residents and consequently carry a heavy burden of grief when residents die. Currently, providing grief support to staff as a routine part of staff health and wellness programs does not commonly occur. This lack of recognition of the emotional impact of grief and bereavement for staff can contribute in staff burnout and increased sick time. Social Work graduate students conducted eight individual staff interviews and prepared a report highlighting workplace wellness strategies that would address grief and loss in LTC. The goal is to develop organizational policies that normalize the staff’s experience with grief and formalized programs available to all LTC staff.

Reduce Professional Hierarchies in LTC homes

Professional hierarchies that exist within LTC homes are detrimental to developing P/EOL programs requiring teamwork. Professional hierarchies impede communication when Personal Support Workers (PSW) or Personal Care Workers (PCW) who know residents and families the best are unable to participate in care planning or to communicate directly with physicians and nurse practitioners. The development of a PC team where each professions role and scope of practice is respected and complimentary facilitates communication and provides a structure for collaborative care planning. The team should have member representation from all departments.

Funding Recommendations

Fund a Long Term Care Centre for Learning, Research, and Innovation dedicated to PC and EOL care in Ontario

The Ontario Ministry of Health recently funded three Centres for Learning, Research, and Innovation. It is recommended that a fourth centre be funded with a focus on P/EOL care.

Increase Funding for Providing EOL Care in LTC

Currently, the MDS-RAI 2.0 includes an indicator for EOL care. J5 asks staff to indicate whether the resident is “end-stage disease; 6 months or less to live.” This indicator is not currently attached to funding. Providing quality EOL care in LTC requires enhanced human resources and we recommend that this indicator be attached to enhanced funding.

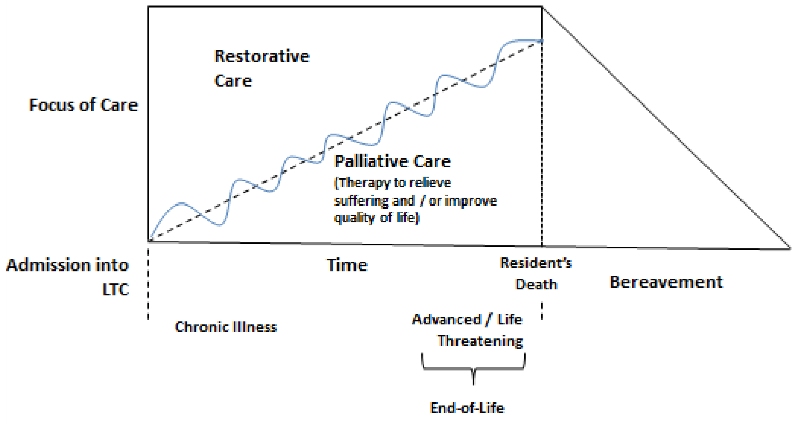
Fund a Marketing Campaign to Promote LTC as a setting that provides Palliative Care

Data indicated that residents and families do not understand that PC can provided in LTC homes. When this is clearly communicated, most families express a preference to have the resident remain in their LTC home until the EOL. In order for the LTC sector to transition itself to be a place that is known to provide residents with quality P/EOL care, LTC homes need to market themselves differently. If LTC homes could market P/EOL care as an essential part of quality resident centred care there would be many benefits to staff, families, residents, and the health care system. These benefits could include more people choosing to die in LTC homes, more communication about P/EOL care, and more opportunity for advance care planning.

Recommendations for Regulations

Adopting CHPCA models of PC

Our research indicates that the current culture within LTC is dominated by the medical model with a focus on restorative care. Currently Advance Care Planning is limited in most LTC homes to the medical directives. It is important that LTC homes move beyond solely discussing medical directives and begin to incorporate advance care planning around social, spiritual, and psychological care needs of the resident and family. This will help residents and families to better understand the scope of care that LTC homes may provide at EOL life and allow staff to learn more about EOL care goals of the resident and family in a more systematic way. The Canadian Hospice Palliative Care Association (CHPCA) provides models of care that LTC homes can use to guide them in providing palliative care concurrently with restorative care. The CHPCA model was adapted by the Alliance to better reflect the fluctuating care needs of residents in LTC with chronic health conditions. This model demonstrates that providing care to residents within LTC homes can simultaneously be restorative and palliative. A common misconception is that when someone is benefiting from palliative care they no longer benefit from restorative care. However, a more appropriate model for providing care within LTC homes is to have both restorative and palliative goals of care and have the focus of care change depending on the illness trajectory. CHPCA also has another model called the Square of Care and Organization. This model outlines the common issues faced by residents and families, the process to providing palliative care, and the different organizational functions and resources that are required to provide a formalized palliative care program. Please see Appendix C to view the CHPCA square of care and organization model. Both of these CHPCA models can be used by LTC homes to guide the development of their palliative care programs.



Use MDS-RAI 2.0 to Identify LTC Residents Needing PC or EOL Care

The MDS-RAI is now mandated for use in all LTC homes in Ontario. The MDS-RAI is a unique tool that could be used for earlier identification of residents who would benefit from a P/EOL care plan. Research shows that earlier identification of residents improves satisfaction and quality of life for residents and families. There has been work done in Canada, Europe and the USA to identify indicators within the RAI tool that should trigger a Palliative Care or EOL care plan. Using RAI data provides homes a systematic way of determining residents eligibility for their programs.

Increased Acknowledgment of Palliative Care and EOL Care in the Ontario LTC ACT
The Ontario LTC Act 2007 stipulates for the first time that LTC homes must provide EOL and palliative care training for staff providing direct care. In the future the Alliance hopes to see palliative care become a mandatory program for LTC homes that is reflective of the CHPCA holistic philosophy.

Palliative Care Accreditation for LTC
Currently, LTC accreditation standards do not specifically include P/EOL care. Having an accreditation with special recognition for palliative care programs would provide an incentive for LTC homes to formalize their programs. It would also assist with marketing LTC homes as locations where excellent palliative care can be received.

Section #3: Conclusion

The role of LTC in the health care system has changed drastically in the last 20 years. LTC homes are now a major location of death in Ontario and trends suggest that their role in providing EOL care will increase into the future. The LTC homes participating in our research embrace their new EOL care role, viewing it as part of the continuum of resident centred care they provide. Our project has demonstrated many successful innovations some of which can be found in the project research posters in the Appendices. At the same time, our project has identified challenges and barriers for LTC homes to implement formalized palliative care programs. Formalized PC programs have been shown to increase resident satisfaction and quality of life in other settings where people die. In an effort to advance the provision of P/EOL care in LTC, we have provided a series of recommendations. We have also compiled some supplemental resources including relevant research and projects from around the world. We would welcome the opportunity to discuss these recommendations or any other issues relevant to implementing formalized palliative care programs in LTC homes.

Appendix A: QPC-LTC Project Background

In 2009, the Social Sciences and Humanities Research Council funded the Quality Palliative Care in Long Term Care Alliance (QPC-LTC) for five years to address the need to develop formal palliative care programs in LTC homes. The Quality Palliative Care in Long-Term Care Alliance is comprised of 31 researchers and 43 organizational partners who actively contribute their expertise to the research project entitled, *Improving Quality of Life for People Dying in Long-Term Care Homes* (see Appendix A for list of Alliance members). The Alliance's primary goal is to develop sustainable, person-focused palliative care programs consistent with the Canadian Hospice Palliative Care Association's Square of Care using a capacity development process. For further information please see the project website www.palliativealliance.ca

The Principal Investigator is Dr. Mary Lou Kelley from Lakehead University Thunder Bay Ontario. The research is conducted with four key partners; Lakehead University, McMaster University, the Municipality of Halton and St. Joseph's Care Group in Thunder Bay. The QPC-LTC Alliance partners are municipal, provincial and national organizations that represent individuals, families, caregivers, health care providers, educators and other stakeholders. There are four long-term care (LTC) homes in Ontario that are study sites for the project: Bethammi Nursing Home and Hogarth Riverview Manor in Thunder Bay, and Allendale Village in Milton and Creek Way Village in Burlington.The primary goal of the research is to improve the quality of life of people dying in LTC homes by developing palliative care programs which integrate the Canadian Hospice Palliative Care Model of Care (see Appendix C). The specific project objectives are:

1. to empower PSWs to maximize their role in caring for people who are dying and their families and support them to be catalysts for organizational changes in developing palliative care
2. to implement and evaluate a 4-phase process model of community capacity development in four LTC sites, and create an evidence-based tool kit of strategies and interventions to support this development.
3. to create sustainable organizational changes that will improve capacity to deliver palliative care programs though empowering PSWs, developing palliative care teams and programs within LTC homes and strengthening linkages with the community partners.
4. to develop knowledge and skills in palliative care and participatory action research

The QPC-LTC methodology is **participatory action research** (PAR), which has two unique features.

- *Participatory* means that those people and organizations that will benefit from the research also fully participate and guide the research
- *Action* means that the goal of the research is to create social change.

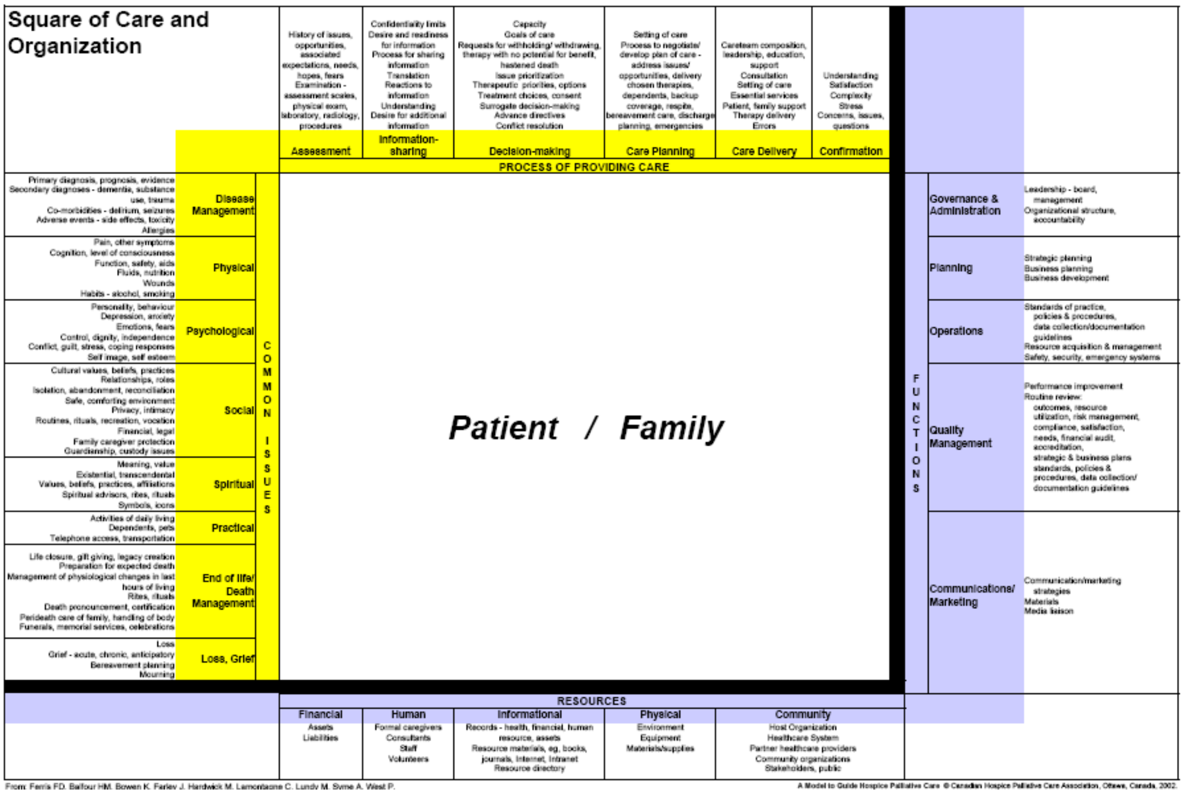
Over the past two and half years, the study has explored issues that serve as barriers to implementing palliative care in LTC homes, and is now assisting facilities in creating environments and specialized services for their residents. Together, researchers, organizational partners and LTC home staff have assessed the needs, implemented interventions and evaluated the results. This is an ongoing process for the next two years. The outcome is development of an evidence based "toolkit” of interventions which can be used by other LTC homes to develop their own palliative care programs. Consequently, this project has benefit to residents, families and LTC homes nationally and internationally. The research also contributes to existing theory on organizational capacity development in a LTC home by implementing by implementing and evaluating a community capacity model to guide the organizational change process. This model outlines a four phase non-linear process for developing palliative care in LTC from the ground up.

Appendix B: Summary of Recommendations

The following table summarizes the recommendations listed above.

Education and Professional Development	Funding	Regulations
→ Build external linkages with key community groups such palliative pain and symptom consultants, Alzheimer's society, hospice volunteers in order to supplement human resources →Increase education regarding palliative and end of life care in regulated college/ university programs that prepare people to work in LTC →Enhance PC continuing education using innovative methods such as simulation lab training, hospice visits, mentoring and specialized Palliative Care for Front Line Workers curriculum →Make grief support programs for staff of LTC home mandatory components of workplace wellness programs → Reduce professional hierarchies in LTC homes and promote interprofessional collaboration and team work between PSW, registered staff, and medical directors	→ Fund an additional LTC Centre for Learning, Research, and Innovation dedicated to palliative and EOL care → Increase funding for resident care when resident is expected to die within 6 months (J5 in RAI-MDS) → Fund a provincial marketing strategy that promotes LTC as place where quality P/EOL Care can be provided	→ Encourage a more holistic model of care by adopting the CHPCA models of palliative care →Increase recognition of the importance of Palliative and EOL care within the LTC Act →Include P/EOL care in Accreditation process to provide incentives for LTC homes to develop, formalize and market their programs

Appendix C: CHPCA Square of Care



Square of Care and Organization

PROCESS OF PROVIDING CARE

Assessment	Information-sharing	Decision-making	Care Planning	Care Delivery	Confirmation
History of issues, opportunities, associated expectations, needs, hopes, fears Examination - assessment scales, physical exam, laboratory, radiology, procedures	Confidentiality limits Desire and readiness for information Process for sharing information Translation Reactions to information Understanding Desire for additional information	Capacity Goals of care Requests for withholding/ withdrawing, therapy with no potential for benefit, hastened death Issue prioritization Therapeutic priorities, options Treatment choices, consent Surrogate decision-making Advance directives Conflict resolution	Setting of care Process to negotiate/ develop plan of care - address issues/ opportunities, delivery chosen therapies, dependents, backup coverage, respite, bereavement care, discharge planning, emergencies	Careteam composition, leadership, education, support Consultation Setting of care Essential services Patient, family support Therapy delivery Errors	Understanding Satisfaction Complexity Stress Concerns, issues, questions

COMMON ISSUES

Primary diagnosis, prognosis, evidence Secondary diagnoses - dementia, substance use, trauma Co-morbidities - delirium, seizures Adverse events - side effects, toxicity Allergies	**Disease Management**
Pain, other symptoms Cognition, level of consciousness Function, safety, aids Fluids, nutrition Wounds Habits - alcohol, smoking	**Physical**
Personality, behaviour Depression, anxiety Emotions, fears Control, dignity, independence Conflict, guilt, stress, coping responses Self image, self esteem	**Psychological**
Cultural values, beliefs, practices Relationships, roles Isolation, abandonment, reconciliation Safe, comforting environment Privacy, intimacy Routines, rituals, recreation, vocation Financial, legal Family caregiver protection Guardianship, custody issues	**Social**
Meaning, value Existential, transcendental Values, beliefs, practices, affiliations Spiritual advisors, rites, rituals Symbols, icons	**Spiritual**
Activities of daily living Dependents, pets Telephone access, transportation	**Practical**
Life closure, gift giving, legacy creation Preparation for expected death Management of physiological changes in last hours of living Rites, rituals Death pronouncement, certification Perideath care of family, handling of body Funerals, memorial services, celebrations	**End of life/ Death Management**
Loss Grief - acute, chronic, anticipatory Bereavement planning Mourning	**Loss, Grief**

Patient / Family

FUNCTIONS

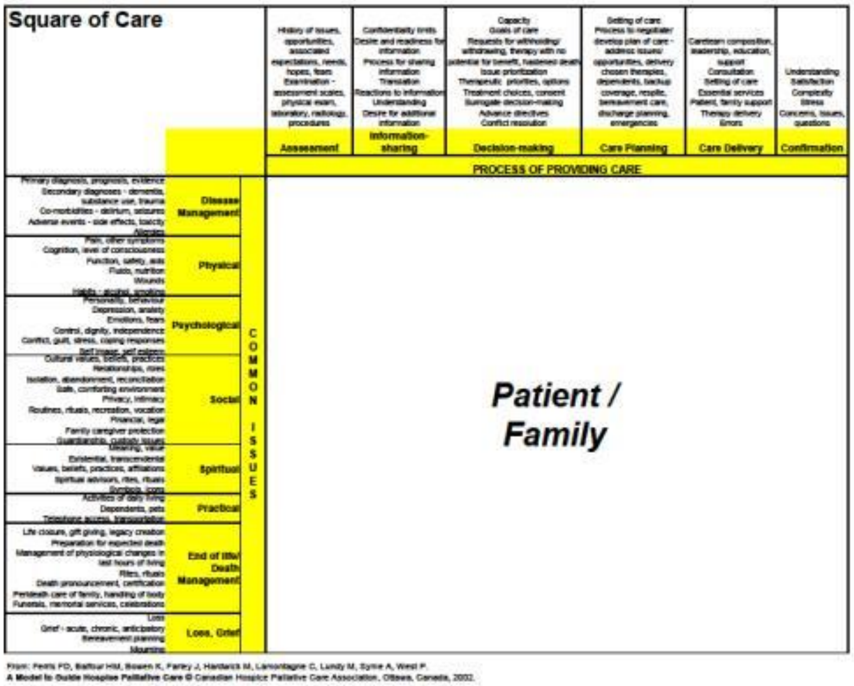
Governance & Administration	Leadership - board, management Organizational structure, accountability
Planning	Strategic planning Business planning Business development
Operations	Standards of practice, policies & procedures, data collection/documentation guidelines Resource acquisition & management Safety, security, emergency systems
Quality Management	Performance improvement Routine review: outcomes, resource utilization, risk management, compliance, satisfaction, needs, financial audit, accreditation, strategic & business plans standards, policies & procedures, data collection/ documentation guidelines
Communications/ Marketing	Communication/marketing strategies Materials Media liaison

RESOURCES

Financial	Human	Informational	Physical	Community
Assets Liabilities	Formal caregivers Consultants Staff Volunteers	Records - health, financial, human resource, assets Resource materials, eg, books, journals, Internet, Intranet Resource directory	Environment Equipment Materials/supplies	Host Organization Healthcare System Partner healthcare providers Community organizations Stakeholders, public

From: Ferris FD. Balfour HM. Bowen K. Farley J. Hardwick M. Lamontagne C. Lundy M. Syme A. West P.

A Model to Guide Hospice Palliative Care © Canadian Hospice Palliative Care Association, Ottawa, Canada, 2002.



Square of Care

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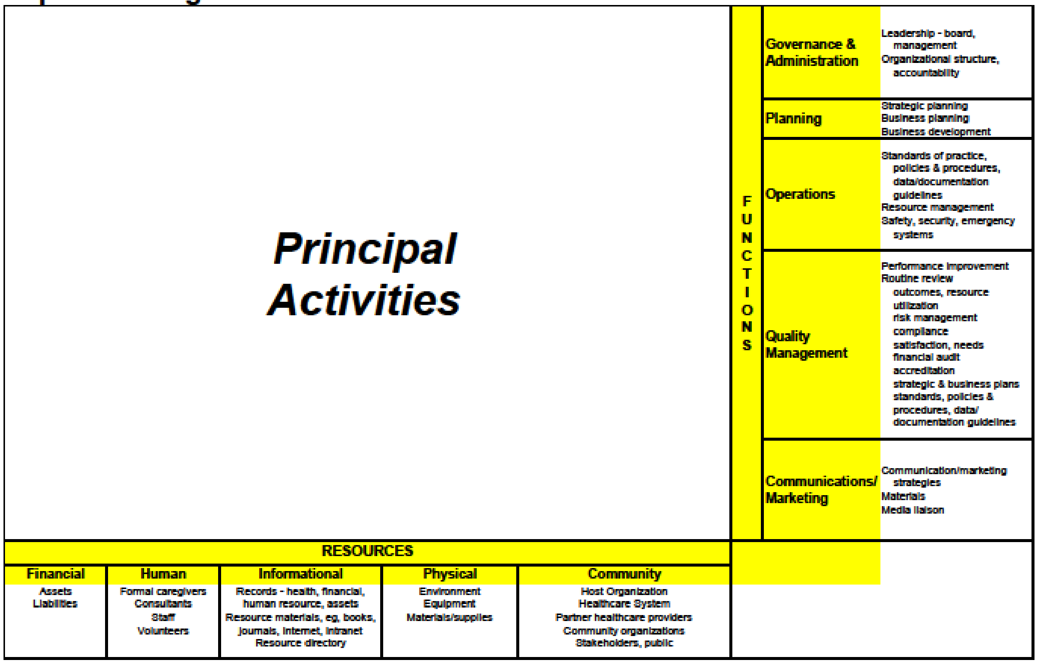
Square of Organization



Principal Activities

FUNCTIONS

Governance & Administration	Leadership - board, management Organizational structure, accountability
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Operations	Standards of practice, policies & procedures, data/documentation guidelines Resource management Safety, security, emergency systems
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Appendix D: QPC-LTC Alliance Additional Resources

Please visit http://www.palliativealliance.ca/conference-abstracts for all our conference posters and presentations. Topics include but are not limited to:

- Developing palliative care programs in LTC homes
- Personal Support Worker competencies
- Simulation lab communication tool
- Multi-Sensory Simulation Lab or Snoezelen therapy
- Resident and family perspective on palliative care in LTC
- Grief and Loss