RURAL OPTIONS FOR RESIDENTIAL HOSPICE CARE

Final Report to the Central East Residential Hospice Working Group

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September 25, 2009
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Executive Summary

There is clear evidence that sustainable residential hospice, in both rural and urban populations, directly improves access to hospital care by reducing the amount of time that patients spend in alternate level of care (ALC) beds – a priority for the MOHLTC and Central East LHIN in the new IHSP for 2010-13 -- with outcomes aligning with objectives of the Triple Aim Initiative developed by the Institute for Health Improvement. The need for rural palliative care options is urgent in CE LHIN, which has large rural districts and the second highest proportion of seniors of all Ontario’s LHINs: By 2016, 16% of the CE population, or over 270,000 people, will be 65 and over. There are currently no operating residential hospices, rural or urban, in CE LHIN. In contrast, the Fraser Health Authority in BC, with a total population nearly identical to CE, is committed to provide full operational funding for 106 hospice beds, including rural beds, by 2010.

There are at least five basic options for funding rural residential hospices, based on current practices in Ontario and other health care jurisdictions, but only three of these options are sustainable.

- **Option one** is for MOH/LHINs to provide partial capital funding for stand alone rural hospices and provide full basic clinical operational funding.
- **Option two** is for MOH/LHINs to provide partial funding for renovations as appropriate for purpose built dedicated hospice suites within buildings housing other programs, such as acute care, and provide full basic clinical operational funding, based on the experience of the Fraser Health Authority in British Columbia.
- **Option three** is for MOH/LHINs to provide no future capital funding but to provide full basic clinical operational funding, based on the Fraser Health experience (which does not provide capital funding for stand alone hospices).

Key Recommendations

1. CE LHIN to **provide full funding for basic clinical operations for all planned residential hospices, both rural and urban, in the CE LHIN.**
2. CE LHIN to immediately **develop and implement a strategy for planning residential hospices across the entire LHIN, in both urban and rural districts,** following the experience of Fraser Health.
3. CE LHIN creates and implements a **strategy for the development of rural palliative care programs throughout the entire LHIN.**
4. CE LHIN fund a community based hospice palliative care program **facilitator** for two rural pilot projects, in Trent Hills and Haliburton, , based on the experience of rural Australia and current rural palliative care priorities of the Australian government.
5. CE LHIN initiate a **two - three bed pilot residential hospice program with The Bridge Hospice in Trent Hills,** following **Option three** above and the NSM LHIN 2008 business plan for a three - five bed pilot project in Hospice Huntsville.
6. CE LHIN initiate a **two - four bed pilot residential hospice program with SIRCH and Haliburton Highlands Health Services** following **Option two** above and the experience of Fraser Health. This would include exploring the feasibility of opening two - four dedicated hospice suites (HHHS), where close to 30% of the 13 acute care hospital beds in the Haliburton campus have patients who are palliative.
7. CE LHIN develops performance measures for pilot rural residential hospices.
Preface

This paper, *Rural Options for Residential Hospice Care*, was commissioned by the Central East Residential Hospice Working Group (CE RHWG) co-chaired by Linda Sunderland, Executive Director, Hospice Peterborough, and Eric Hong, Director of Corporate Development, Yee Hong Centre for Geriatric Care. Funding for it was provided by Central East Local Health Integration Network (CE LHIN). The primary author is Dan Dempster who was engaged by TGA Policy Solutions inc. (TGA) for this important assignment. Mr. Dempster was supported by Trent Gow, Principal Officer of TGA, the company that was selected by competitive process for this consulting mandate.

This stand-alone paper is a complement to and a component of a broader study also done by TGA for CE RHWG, *Residential Hospices in the Area Served by the CE LHIN: Planning, Building, Operating and Sustainability*.

The key underlying difference between the papers is one of focus. Like the current analysis and advocacy of the Hospice Association of Ontario in the area of residential hospice, the broader paper addresses the subject of residential hospices largely from the lens of a ten bed residential hospice – the generally accepted best model for the provision of residential hospice care in an urban setting. Yet the vast majority of the land area served by CE LHIN (16,673 km2) - home to a small minority of the residents - is made up of suburban towns, rural farm communities, cottage country villages and remote settlements. Ten bed hospices are not practical (for reasons of proximity and cost, among others) to meet the needs of residents in these rural and remote locales. But these needs are real and they are escalating rapidly in pace with the dramatic aging of the population and the parallel relocation of retiring people to rural and remote areas.

While there is a growing -- if still insufficient -- body of evidence in and around the planning, building, operating and sustainability of ten bed hospices, there is a paucity of analysis and only a smattering of one-off empirical examples associated with approaches to residential hospice care in rural and remote areas. As such, it is commendable for CE RHWG to have commissioned this study and for CE LHIN to have funded it. It is only by identifying, defining and understanding a key gap in the continuum of health care delivery -- which this is -- that it can be filled in a creative, cost-effective, caring way.

Introduction

The ongoing – and largely unmarked - failure to develop and implement community based models for the provision of hospice palliative care options for rural and remote areas of Ontario – in CE LHIN and elsewhere - is reaching a crisis point, in terms of the sizable and growing unmet needs for this care by residents of these areas. Recent literature indicates that rural populations in Canada, Australia and the United States have limited access to and options for effective and integrated hospice palliative care within their communities. The result is that many palliative rural residents end up in acute care beds in small local hospitals or in urban centres far from their community and family supports. In Australia, which has an aging rural demographic similar to that of Ontario and Canada, the federal Department of Health and Ageing recognizes the
urgency of this issue and has made the development of options and models for the delivery of rural palliative care a national priority. But the work has only just begun.

The need to enhance hospice palliative care options locally will become more pressing in the immediate future in Ontario, where rural communities now have populations with a higher proportion of seniors compared to urban areas, and this trend escalates in the demographic projections of LHINs with large rural districts. The North Simcoe Muskoka (NSM) LHIN and CE LHIN in particular have the first and second highest proportion of seniors respectively of all Ontario’s LHINs. In NSM LHIN, e.g., 19% of the population will be 65 and over within ten years, and 8% will be 75 and over. In CE LHIN, 16% of the population, or over 270,000 people, will be 65 and over by 2016. Neither LHIN has any residential hospice beds – although Hospice Simcoe has a leading-edge ten bed hospice ready to open but stalled by inadequate operating funding, a frustrating matter that is addressed in the broader companion report to this one.

It is urgent that CE LHIN and all LHINs with rural and remote populations in Ontario facilitate and support development of rural options for effective and integrated hospice palliative care, including options for sustainable smaller residential hospices. There is clear evidence that sustainable residential hospices, both rural and urban, also directly improve access to hospital care by reducing the amount of time that patients spend in alternate level of care (ALC) beds, which are both a MOHLTC priority and a CE LHIN priority in the new IHSP for 2010-2013. The Fraser Health Authority (FH) experience in British Columbia, for example, demonstrates that FH’s commitment to fully funding basic operations for 106 residential hospice beds by 2010 has already positively impacted the amount of time patients spend in ALC beds, in that 33% of all deaths in FH are now in residential hospice, and deaths in hospital have fallen from 66.9% to 48% over the last three years, with the result that some acute beds have been closed, ED wait times and length of stay have been reduced and funding has then been reinvested in community and hospice programs.

In Ontario, NSM LHIN also recognizes explicitly this direct connection between augmenting residential hospice beds and reducing patient time in ALC beds. In August 2008 it drafted a business case and rationale for providing full operational funding for 42 new residential beds across the LHIN over the next three years on a high priority basis. The 42 beds would be distributed among one urban hospice and five rural and semi-rural hospices, including a three bed pilot rural project with Hospice Huntsville, Muskoka. CE LHIN is also in the early stages of addressing this issue, which impacts its ALC beds, and allocated resources for this study to assist the region in its planning and decision making regarding the building, operating and sustainability of residential hospices. Of particular interest in the study are sustainable options for residential hospice services in rural communities, the subject matter of this report.
**Research Methodology**

- Reviewed and analysed the ‘Alternate Level of Care Systems Issues and Recommendations’, June 2008, prepared by CE LHIN ALC Task Group
- Met with and interviewed key representatives from all planned rural residential hospices in CE LHIN, including The Bridge Hospice in Trent Hills and SIRCH Community Services and Consulting in Haliburton, and CE LHIN
- Identified how unique rural and remote residential hospice care challenges have been addressed in other LHINs with rural and remote challenges similar to CE LHIN, such as NSM LHIN
- Developed and analysed a questionnaire distributed by the Hospice Association of Ontario (HAO) to all operating and planned hospices across Ontario, urban and rural, which focussed on issues and options for operational sustainability
- Searched for evidence of and reviewed best practices for rural residential hospice in the Pallium Project and other Canadian jurisdictions, such as Fraser Health in British Columbia
- Searched for international options for delivery of rural hospice palliative care, with a focus on Australia, which has recently made delivery of effective and integrated rural hospice palliative care a national priority.

**Literature Review Summary**

What is particularly striking about the over 150 published studies on rural palliative care over the last decade is that most work identifies the problems but does not come to grips with any tangible solutions in delivering effective palliative care in rural regions.

In a recent 2009 article on ‘Rural Palliative Care: A Comprehensive Review’ in the *Journal of Palliative Medicine*, Carol Robinson et al note that international ‘research on rural and remote palliative care is still in its infancy’ and that ‘the body of research literature is small and eclectic, which means there is little strong evidence to inform palliative policy and service development in rural settings’.6

There is, however, one emerging conceptual model of rural palliative care based on the Canadian experience in six provinces, including Ontario, which emphasizes the importance of partnership and capacity building from the ‘ground up’.7 This model could be useful in establishing the framework and timeframe for developing an integrated rural hospice palliative care program, which depending on the needs of the community, may include development of a small residential hospice.
Key Observations

The following observations are based on consultation with key informants in Ontario and Canada, analysis of HAO’s June 2009 questionnaire, review of regional best practices in Canada and international peer reviewed literature on rural palliative care.

- Residential hospice in rural areas will have a better chance for development, acceptance and integrated service delivery when built upon an existing and sustainable community-based hospice palliative care program or initiative.

- Rural hospice palliative care needs a “whole community” approach: community-focused development is the essential issue.

- Building a rural hospice palliative care program, therefore, is essentially an ‘inside job’. While conceptual models of care and appropriate levels of funding from the Regional Health Authority or LHIN are helpful and needed, ‘imposed’ external interventions are not major factors for sustainability. One model does not fit all.

- The process of building a rural palliative program is incremental, takes time, and conceptually may be seen to demonstrate four phases or pre-conditions [see Appendix A].

- Policies and procedures are needed -- but working on these at the very outset of a new rural initiative can bog down progress, and therefore are best not developed in detail until the community is effectively ‘growing the program’.

- In Australia, where rural palliative care is a national priority, it has been determined that community development of hospice palliative care must also be a facilitative process. In launching the Rural Palliative Care Project, with new funding to be allocated to 36 rural divisions across Australia over 2008-10, the Australian Government recognizes that effective implementation requires an assigned facilitator who must be someone from within the local community and who is competent to fill the role requirements. The facilitator will be:  
  o required to provide initial leadership in starting the building process and liaising with other potential team members; and 
  o responsible for bringing the community group together helping it to start its work.

  The purpose of the funding is to implement and reorient rural palliative care services in order to provide sustainable models of rural palliative care delivery that can be adapted to address the local needs of rural communities throughout Australia. These models will be reviewed in 2010 for examples of best practices in the 36 rural regions.

- As with larger ten bed hospices in Ontario, operations in smaller rural residential hospices are not sustainable unless there is full funding for basic clinical operations.
• Small residential hospices that do try to operate while receiving no funding from the MOHLTC/LHIN, and which rely on volunteers and existing CCAC services, are certainly dedicated and resourceful in attempting to meet the need of their community, and do valuable work. They are unable, however, to adhere to the HAO basic standards for residential hospice care, or to meet expectations of 24/7 nursing care as outlined in the MOHLTC’s ‘Residential Hospice: Funding and Accountability Overview’, May 2006

• Capital funding from the MOHLTC for residential hospices has not been planned strategically, and the impact of this lack of planning is particularly evident in rural Ontario.
  o One rural six bed hospice, Hospice Renfrew, recently received capital funding -- but only after it was built and as a result of a visit at its opening by then Health Minister George Smitherman, who expressed astonishment that it had not already been designated for capital funding as were other urban hospices, some of which are still years away from building.

• Not all rural residential hospices need be stand alone buildings like Hospice Renfrew, but can operate as dedicated hospice suites in shared facilities, among other approaches:
  o It has been the Fraser Health (FH) experience that ten beds is the smallest size possible to provide efficient and effective staffing for a dedicated hospice residence, which is problematic for smaller rural communities.
  o Nevertheless, rural hospice beds are also seen by FH as creating a more appropriate care setting for patients from rural areas who are dying, as well as providing the favourable economics that occur when a shift is made away from acute care.
  o In small communities that do not have the population and/or resources to establish a dedicated hospice residence, such as Hope BC with a population of 9,000, two designated, purpose built hospice suites have been established within Fraser Canyon Hospital, an acute care facility with ten beds.
  o FH recommends this model for other communities that are unable to establish a designated hospice residence at this time, but with sustainable operational funding from FH are able to arrange for designated hospice beds within a subacute unit/ transitional unit or some other suitable locations within an acute care facility.8

• Based on the Fraser Health experience, NSM LHIN business case, analysis of the HAO questionnaire, and information from key informants in CE LHIN, it is evident that when basic clinical operating costs are covered, smaller communities have greater capacity and a better business case to fundraise for stand alone buildings or renovation costs in a shared facility
• Each rural community is unique and will support designated hospice beds according to its own culture, tradition, demographics, resources and partnerships.

• Since rural residential hospices have a better chance for development if they are built upon existing and sustainable hospice palliative care community programs with extensive outreach, it is noteworthy that, unlike Australia, MOHLTC/LHIN funding for community hospice programs, both rural and urban, has no consistent rationale or strategic foundation, with funding coverage ranging from less than 20% to 77% of total hospice operations.

Current Status of Residential Hospice Funding and Rural Funding Options

As noted in the broader companion paper, the current formula of $580,000 for a ten bed hospice is less than half of what is required for basic operations, and there is an emerging crisis in Ontario with many established hospices now under threat of having to close beds, and one hospice in NSM LHIN, fully built and equipped, unable to open because of its board’s concern for even short term sustainability and liability.

For rural hospices with fewer beds, such as Hospice Renfrew, the issue of sustainability is equally apparent. Hospice Renfrew, with six beds, receives $460,000 from the MOHLTC, which is 32% more per bed per year than a ten bed hospice receives, and reflects the higher cost per bed for smaller hospices in maintaining the 24/7 care standards established by HAO, which is a condition of Ministry funding. The $460,000, however, is less than half Hospice Renfrew’s total operating budget of $950,000. It is not a sustainable position for a small rural community to have to fundraise an additional $500,000 annually, year after year.

The authors are aware that as of September 25, 2009, MOHLTC and the 14 LHINs are in the process of determining if and how best to fund residential hospices, given current legislation, should there be consensus to supplement the currently accepted but inadequate formula of $580,000 for a ten bed hospice. This funding currently flows from MOHLTC to the CCAC, and then from the CCAC to the residential hospice. We also hope and expect that there will be consensus on a suitably sufficient/appropriate level of funding for operations and capital.

At least four LHINs have taken or allowed initiatives to increase residential hospice funding in their jurisdictions, including a pilot project in NSM LHIN for a rural residential hospice. MOHLTC, however, has maintained that there must be consistency in how and where all LHINs may fund residential hospice initiatives across the province. It is the expectation of MOHLTC that there must be agreement on these funding issues and solutions from all 14 LHINs.

The following options include those based on current practices, and the authors conclude, based on the evidence, that only options one to three are sustainable in the long term. Option four is the unsustainable current status quo, and option five is the default position for at least one resourceful rural hospice that receives no MOHLTC/LHIN funding for operating or capital costs.
Option One

MOH/LHINs to provide partial capital funding for stand alone rural hospices and provide full basic clinical operational funding

- This is clearly the best option for the development of sustainable rural residential hospices
- The 70/30 (Ontario/community) model used by the MOHLTC and Energy and Infrastructure in funding the capital costs of hospitals would seem relevant in principle and appropriate for rural residential hospices
- Over 20 residential hospices have already received partial capital funding from MOHLTC, including one rural hospice, which was welcome and appreciated, and in some cases unexpected. The funding amounts, however, do not appear to flow from any discernable formula. Furthermore, neither the timing of the funding nor the choice of funding recipients appears to be planned following a clear and public strategy for the province, which is necessary moving forward.
- No residential hospices in Ontario currently receive full basic clinical operational funding - most receive only 40-50% of what is actually required
- Note in option two below that Fraser Health is committed to providing basic operating funds for rural hospice beds; these funds are allocated as part of the re-organization of acute care services or the result of new funding allotments.

Option Two

MOH/LHINs to provide partial funding for renovations as appropriate for purpose built dedicated hospice suites within buildings housing other programs, such as acute, sub-acute, complex care, assisted living etc., and provide full basic clinical operational funding, to be cost shared, where appropriate, with the host facility

- This is also a workable option for the development of sustainable rural residential hospices, based on the experience of Fraser Health in BC.
- Fraser Health, with a population total nearly identical to that of CE LHIN, is committed to providing operational funding for core staffing and operations for 106 residential hospice beds for its population of 1.54 million by 2010, serving urban, semi-rural and rural populations. These funds are allocated as part of the re-organization of acute care services or the result of new funding allotments.
- In small communities, therefore, that do not have the population and/or resources to establish a dedicated hospice residence, such as Hope BC, with a population of 9,000, two designated, purpose built hospice suites have been established within Fraser Canyon Hospital, an acute care facility with ten beds.
- Fraser Health emphasizes that it is essential that all rural beds in buildings housing other programs be designated and designed specifically as permanent hospice suites, rather than “swing beds”.

Fraser Health, with a population total nearly identical to that of CE LHIN, is committed to providing operational funding for core staffing and operations for 106 residential hospice beds for its population of 1.54 million by 2010, serving urban, semi-rural and rural populations. These funds are allocated as part of the re-organization of acute care services or the result of new funding allotments.
• Patient assignments will ideally be arranged so that one nurse on each shift cares for all the hospice patients plus an additional number of subacute/acute, rehab etc. patients in the same building to bring him/her to a full workload.

• Fraser Health does not have capital funding available for construction of hospice beds in a stand alone building. Any new construction or capital funding requirements are the responsibility of the project partners. Some renovation work as appropriate, however, may be funded through Fraser Health. Fraser Health also leases purpose-built space within buildings housing other programs such as complex care, assisted living, etc.

**Option Three**

MOHLTC/LHINs to provide no future capital funding but to provide full basic clinical operational funding

• This is also a workable option for the development of sustainable rural residential hospices, based on the Fraser Health experience and information from key informants in CE LHIN

• In addition, **NSM LHIN recently drafted a business case and rationale in August 2008 for providing full operational funding for new residential beds across the LHIN - urban and rural - but not capital funding**.

• The business case observes that many people are admitted to hospital or stay longer in an ALC hospital bed than required because rural regions do not have enough community care options to manage their conditions.

• A NSM LHIN priority identified is to enhance options along the continuum of care, therefore, is the creation of 42 new residential hospice beds over the next three years.

• The 42 beds would be distributed among one urban hospice and five rural and semi-rural hospices, including a three bed pilot project with Hospice Huntsville, Muskoka.

• Currently, there are no residential hospice beds available in NSM LHIN.

• The NSM LHIN business case noted that hospices in small communities would face significant challenges in fundraising for both operating and capital, and therefore the provision for full operating funds is essential to support these small communities to raise the necessary capital funds for the building or renovation.

• This is also a cost effective solution since hospice beds are normally less than half the cost of acute care beds

• The NSM LHIN business case fits with Cancer Care Ontario’s Palliative Care Directions and Strategies and is supported by North Simcoe Muskoka LHIN’s local Regional Cancer Care Program

• NSM LHIN concludes in its business case that ‘failure to address the need for residential hospice care will continue to increase the burden of care in acute care settings. Alternate level of care (ALC) days will rise with each failure to move acute care patients to other levels of care, when and where appropriate. There is an urgency to act to improve hospital-community flow’.
Option Four

MOHLTC/LHINs to continue to provide partial capital funding and continue to fund only a percentage of actual clinical operational costs

- This is evidently not a sustainable option, yet this is the current situation for all operating hospices in Ontario, where most have received some one-time ‘capital’ funding, and where ten bed urban hospices receive $580,000 annually, and a rural hospice with six beds receives $460,000, which is only 40-50% of actual costs
- While partial capital funding is welcome, it is clear, based on the experience of Fraser Health, the 2008 business case of NSM LHIN, analysis of the HAO June 2009 questionnaire, and information from key informants from planned residential hospices in CE LHIN, that it is guaranteed ongoing full basic clinical operating funding, not one time capital funding, which is essential for the development and sustainability of residential hospices, rural and urban. Evidence indicates that communities are better able to raise capital funds when ongoing full operating funding is assured.

Option Five

MOHLTC/LHINs to provide no capital or operating funding, and allow small local rural initiatives to use volunteer and existing CCAC services in ‘cluster care’ arrangements

- This is currently the default option in at least one rural region that has identified the need and pulled together to provide residential hospice care in their community, and yet has no support from MOHLTC/LHIN for capital or operating funding
- While a good example of a ‘whole community’ initiative, this is not a guaranteed sustainable ‘model’ for all rural communities, and is only an interim option until appropriate operating funding is in place.
- An example of this community based arrangement is Hospice North Hastings, in Bancroft SE LHIN, which is a two bed hospice, operating for two years in a house already fully paid off, and an extension of a well established hospice community program which has existed for 13 years
- The Hospice uses existing CCAC contract services and volunteers. While the Hospice is trying to meet the need with existing resources, it does not have 24/7 RN coverage on site (an RN is on call only overnight, with a PSW is on site). The hospice and community, therefore, simply do not have the resources needed to meet HAO’s residential hospice standards, which are based on the nationally accepted ‘Norms of Practice’ of the Canadian Hospice Palliative Care Association.9
- What is particularly significant about this initiative, however, is that 95% of referrals are from four regional hospitals, including Kingston and Belleville, and from the CCAC as an alternative to hospital, which at a 75% occupancy rate impacts significantly in reducing ALC bed days
- The Hospice has solid community support, but relies extensively on the resourcefulness, time and energy of the executive director, which again raises the issue of sustainability of this model in other communities
Recommendations

1. Central East Hospice Palliative Care Network (CEHPC Network) should urge CE LHIN to provide full funding for basic clinical operations for all planned residential hospices, both rural and urban, in CE LHIN. Based on the Fraser Health experience, this initiative will enhance the patient experience of care, including quality, access and reliability of care; improve caregiver and family health; and reduce the number of ALC days, and the cost per capita of care. This outcome aligns with objectives of the Triple Aim Initiative developed by the Institute for Health Improvement.

2. CEHPC Network should urge CE LHIN to immediately develop and implement a strategy for planning residential hospices across the entire LHIN, in both urban and rural districts, following the experience of Fraser Health. The CE LHIN population is nearly identical to that of Fraser Health, which is committed to at least 7 hospice beds per 100,000 population in both urban and rural communities. In CE LHIN, this would require planning resources for at least 105 new residential hospice beds immediately, including two-three bed hospices in rural areas where community palliative care programs are in development.

3. CEHPC Network should recommend to CE LHIN that it create and implement a strategy, in consultation with key informants from rural communities, for the development of rural palliative care programs throughout the entire LHIN, based on projected demographic trends, palliative care needs and community resources. This aligns with the recommendations of the ‘Alternate Level of Care Systems Issues and Recommendations’, June 2008, prepared by the CE LHIN ALC Task Group. These include recommendations to:
   - Extend CCAC service maximums set by provincial regulation for nursing, homemaking services and enhanced personal support and the capacity...to keep clients in the community as long as possible;
   - Increase community support services for in-home personal support, homemaking and caregiver respite; and
   - Ensure a core basket of community services... is equitably available across the Central East LHIN.10

4. As part of this rural strategy, CEHPC Network should recommend the CE LHIN fund a community based hospice palliative care program facilitator for two rural pilot projects, in Trent Hills and Haliburton, based on the experience of rural Australia and current rural palliative care priorities of the Australian government.
   - The facilitator would be from and already active within the pilot rural communities, and be funded for a two year period, to provide initial leadership in starting the building process and liaising with other potential team members to develop and enhance the program. This is a key prerequisite for development of a sustainable residential hospice program.
   - CEHPC Network should review the Australian ‘Palliative Care Tool Kit’ (PCTK) principles used by Australian rural facilitators [see Appendix B]
5. CEHPC Network should recommend to CE LHIN that it immediately initiate a **two-three bed pilot residential hospice program with The Bridge Hospice in Trent Hills**, following **option three** above and the NSM LHIN business plan for a pilot in Hospice Huntsville. This recommendation is in addition and complementary to recommendation #4 above.

- The Bridge Hospice already has a draft business plan and is confident that they can raise the capital for a stand alone two bed rural hospice, to be located in Warkworth, by 2010.
- The Bridge Hospice plan includes one paid coordinator position, staffed at 0.8 FTE, who could also be funded by CE LHIN as the pilot rural community facilitator.
- The Trent Hills Family Health Team would be approached to be responsible for administration, i.e. payroll and benefit administration, assisting with making any funding applications, etc.
- The pilot hospice could use existing CCAC or other contracted services, and CE LHIN, through CE CCAC, would ‘top up’ the difference to insure 24/7 RN coverage to meet HAO residential hospice standards
- Based on the experience of Hospice North Hastings in Bancroft, one could project that up to 95% of referrals would be from regional hospitals and from CCAC as an alternative to hospital.
- The hospital in CE LHIN that experienced the most severe ALC pressure with the longest average length of stay in 2006/07 was Campbellford Memorial Hospital at 67 days ALOS or 40.7% of total days in site\(^1\)
- The CEO of Campbellford Memorial Hospital notes that in the 34 bed hospital at least 60 patients each year are palliative, of which 40 would benefit from residential hospice care. This figure does not include palliative patients from the region who may have been sent to other hospitals providing palliative care.
- An average of a length of stay of 21 days at the hospice for 40 patients would free up 840 bed days at the hospital, which serves a population of 30,000 people in Northumberland and Hastings. A 2 bed hospice at 90% occupancy would provide 657 bed days, and take in patients at less than half the cost of a hospital bed

6. CEHPC Network should recommend to CE LHIN that it immediately initiate a **two-four bed pilot residential hospice program with SIRCH and Haliburton Highlands Health Services** following **option two** above and the experience of Fraser Health. This recommendation is in addition and complementary to recommendation #4 above.

- Explore the feasibility, in collaboration with SIRCH, of opening two-four dedicated hospice suites by 2010 in Haliburton Highlands Health Services (HHHS), where close to 30% of the 13 acute care hospital beds in the Haliburton campus have patients who are palliative. This proposed initiative has the full support of Paul Rosebush, CEO of HHHS, who anticipates equal enthusiasm and support from the HHHS Board
• Next to Campbellford Memorial Hospital, hospitals in CE LHIN that experienced the most severe ALC pressure with the longest average length of stay in 2006/07 were the Haliburton Highlands Health Services at 33.3 days ALOS, and Peterborough Regional Centre (which also admits many patients from Haliburton) at 29.9 days ALOS
• Donor fatigue is a determinant for any capital campaign for a ‘stand alone’ building in Haliburton, which could be seen to be in competition rather than aligned with a hospital campaign. Capital costs for renovations for dedicated hospice suites in the hospital, however, could either be covered by Infrastructure Ontario, or be aligned with and included in the hospital campaign, an arrangement similar to the experience of the Southlake hospice and hospital in Central LHIN
• Following the Fraser Health experience in Hope BC, which has a population of only 9,000 and two designated hospice beds in a ten bed acute care hospital, a shared use arrangement in the HHHS would be a better use of sparse human resources. This shared care arrangement, therefore, appears be a better option than a stand alone facility in the Haliburton Highlands, which has an aging population spread over a large area, yet which already sees HHHS, with campuses in Haliburton and Minden, as centers of community based health care services.
• There will be increasing demand for local hospice palliative care resources in Haliburton because many people now chose to live at their cottages from early spring to early winter, swelling the 16,500 base population of Haliburton to 60,000 – 70,000 at peak times. Almost all cottage residents who extend their stays are retired, and the majority are over 65 years old. The County of Haliburton now has the second highest percentage of seniors of any county or equivalent in all of Canada. Two hospice beds, therefore, may be a start in 2010, but four beds will probably be required in the every near future to meet anticipated demand.

7. CEHPC Network should recommend to CE LHIN preliminary performance measures for pilot rural residential hospices. These could include:

• Decreased number of ALC days related to palliative conditions
• Decreased length of hospital stay for palliative conditions
• Decreased ED visits by palliative patients that could be managed elsewhere
• More appropriate use of acute care resources
• Improved patient/family satisfaction
Conclusion

Rural residents in CE LHIN have limited access to and options for effective and integrated hospice palliative care within their communities. The unfortunate result is that many palliative rural residents end up in acute care beds in small local hospitals or in urban centres far from their community and family supports.

This trend has a direct impact on the ALC occupancy rate for non-acute patients in acute care beds in CE LHIN hospitals, which was an estimated 18% in 2008 and equates to over 165 hospital beds. Without options for community based care, the number of ALC beds will continue to grow in CE LHIN, with its rapidly aging population.

Although ALC occupancy rates were often identified as a hospital problem, it is clear today that this is both a CE LHIN system issue and community issue that cannot be resolved by hospitals trying to manage alone. As noted in the foreword of ‘Alternate Level of Care Systems Issues and Recommendations’ of CE LHIN ALC Task Group:

Patients, families, health service providers in the hospital and in the community are challenged to act together and to share responsibility for reducing the ALC volumes by 10% per year while ensuring the right level of care is delivered in the right place and at the right time with the right resources to the residents of the Central East LHIN.12

Based on the evidence from the experience of Fraser Health in BC, one effective community based solution for CE LHIN is obvious - planning strategically for and investing in residential hospice beds, in both rural and urban districts, directly and quickly reduces patients’ times in ALC beds and is a cost effective and appropriate level of service which enhances the palliative patient’s experience of care.

Fraser Health, with a population of 1.54 million, which is nearly identical to the population of CE LHIN, is now committed to fully funding basic operations for 106 hospice beds in nine hospices in urban, semi-rural and rural communities by 2010, and has the strategy and rationale for implementation.

CE LHIN currently has no residential hospice beds; and yet now has a strategic opportunity, by investing modest resources in two rural pilot projects, to be a leader in Ontario and advance its mission of ‘the right care, at the right place, at the right time’

The communities and health care providers in Trent Hills and the County of Haliburton -- which are served by the two hospitals with the most severe ALC pressure in CE LHIN -- are ready and willing to move forward collaboratively in planning, developing, integrating and operating rural residential hospices; yet they also require strategic commitment and sustainable resources from CE LHIN to do so immediately.

The urgent need for effective rural hospice palliative care is well documented in Canada and is growing particularly rapidly in rural Ontario. An evidence-based and cost effective solution for meeting this pressing need in CE LHIN is clear and achievable. The time for action is now.
Appendix A

Mary Lou Kelly at the University of Waterloo has recently brought forward a promising conceptual model for development of effective and collaborative rural palliative care programs, based on research in six provinces, including Ontario. [Kelly ML: Developing rural communities’ capacity for palliative care: A conceptual model. Journal of Palliative Care, vol 23, 2007].

Kelly observes that the process is incremental and conceptually may be seen to demonstrate four phases or pre-conditions.

- **Antecedent conditions are the foundation – rural communities at the outset must build on what they have**
  - Is there a collaborative general practice in place or effective FHT?
  - Is there a sufficient basic health services infrastructure in the community?
  - Does the community have a sense of control over how it will care for the dying?

- **Nothing happens without a catalyst for change**
  - A catalyst is something which shakes up the current approach to care for dying people and triggers collective action to improve care for the dying in the community.
  - Examples of a catalyst could be a ‘bad death’; a local champion taking the lead; new project funding/development initiative; or MOHLTC/LHIN policy change

- **Building the local team is essential**
  - Because there tend to be few or no palliative care specialists in rural communities, general providers must join together to improve care of the dying and develop collaborative hospice palliative care
  - Dedicated providers, and the right people must be involved, notably family physicians, CCAC etc

- **Growing the program takes time (years)**
  - The team builds and extends into the community to deliver hospice palliative care
  - Clinical practices eventually change
  - Ongoing education is essential and must be delivered for all community providers
  - Community relationships then build to improve service delivery
  - Policies and procedures are then developed and additional resources sought
Appendix B

Australia’s Palliative Care Tool Kit (PCTK)

Rural palliative care is a key health care priority in Australia. The Australian Government’s Department of Health and Ageing announced in April 2008 funding of more than $6.5 million to provide more coordinated care for rural Australians with a life-limiting illness.

In launching the Rural Palliative Care Project, with new funding to be allocated to 36 rural divisions across Australia over 2008-10, the Australian Government recognizes that effective implementation rural palliative care service delivery that can be tailored to address the local needs of rural and remote communities throughout Australia requires a facilitator and a ‘tool kit’.

The 36 pilot rural regions in Australia will therefore be using a Palliative Care Tool Kit (PCTK) which was developed in Australia using an evidence-based approach.

There are five key principles to the kit:

1. **A community initiative** - where the community needs to be involved in all stages;

2. **A facilitative process** - where implementation requires a facilitator and must be someone from within the local community who is competent to fill the role requirements;

3. **Leadership** - where the facilitator will be required to provide initial leadership in starting the building process and liaising with other potential team members;

4. **Work focussed** - in that the facilitator will be responsible for bringing the community group together helping it to start its work;

5. **Group effort** - where the community group and the clinical team will be responsible for using the PCTK to develop and maintain services.

The PCTK uses the principles of the World Health Organisation definitions of palliative care and draws upon the best evidence available.

The PCTK has a structured approach that guides the facilitator through two phases and provides assessment questions, guiding principles and practical strategies.

The resource kit includes information such as current definitions of palliative care, tips on team building, information of web based resources, and brainstorming techniques.

The PCTK assists in guiding the development of the community group by reviewing the existing approaches to palliative care and in establishing the revised palliative care service.
Endnotes


2 Government of Australia, Department of Health and Ageing, Rural Palliative Care Funding Announcement, 15 April 2008.

3 TGA Policy Solutions, Residential Hospices in the Area Served by the CE LHIN: Planning, Building, Operating and Sustainability, August 2009

4 Tayler C et al: Fraser Health Palliative Care Program, June 2009.

5 As of August 20, 2009 the pilot project is on hold pending agreement between the 14 LHINs and MOHLTC on how at what level residential hospice funding may be increased or initiated.


8 Fraser Health Hospice Residence: Creating a healing and caring environment at the end of life. August 2007; Fraser Health Authority Plan for Hospice Beds in Locations other than a Hospice Residence, February 2003.


11 Ibid., 15

12 Ibid., iii