

# **Erie St. Clair End-of-Life Care Network Hospice Palliative Care Education Blueprint**

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## **Cultural Education**

Evaluation Report

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**For:**

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## Glossary of Terms

Average (+/-)	Average is calculated as the mean score ; +/- = standard deviation, which is the average distance between individual scores from the overall average score.
CAPCE	Comprehensive Advanced Palliative Care Education
CCAC	Community Care Access Centre
COPD	Chronic Obstructive Pulmonary Disease
DNR	Do Not Resuscitate
EOL/ EOLC	End of Life / End-of-Life Care
ESC EOLCN	Erie St. Clair End-of-Life Care Network
ESAS	Edmonton System Assessment Scale
LHIN	Local Health Integration Network
LTC	Long-Term Care
NP	Nurse Practitioner
OSCMC	Ontario Cancer Symptom Management Collaboration
OT	Occupational Therapy
OTN	Ontario Telehealth Network
PCR	Palliative Care Resource
PPS	Palliative Performance Scale
PPSMC	Palliative Pain and Symptom Management Consultant
RT	Respiratory Therapy
SRK	Symptom Response Kit
SWO PPSMCP	Southwestern Ontario Palliative Pain and Symptom Management Consultation Program
PSW/HSW	Personal Support Worker/ Home Support Workers
RN/ RPN	Registered Nurse/ Registered Practical Nurse
WIFN	Walpole Island First Nation
WRCC	Windsor Regional Cancer Centre

# Education Blueprint Evaluation Executive Summary

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## Erie St. Clair End-of-Life Care Network Hospice Palliative Care Education Blueprint

### INTRODUCTION

The Erie St. Clair End-of-Life Care Network has secured funding for several initiatives aimed at creating and supporting an integrated hospice palliative care system in this region. One of these initiatives is a multi-year framework for palliative / end-of-life care education consisting of the following initiatives:

- 1. Volunteer Education:** Implementation of strategic volunteer education planning sessions; training programs to enhance the scope of volunteer training (e.g., Hands on Care training, Story Telling Project,) and promotion of the 'Share the Care' model to support informal caregivers/ volunteers.
- 2. Cultural Education:** Working with First Nation representatives to identify the palliative care needs of this community develop strategies to meet these needs and to assess the training needs of health care providers working within the Walpole Island First Nation community.
- 3. Skill Specific Education for Care Providers:** Implementation of two education programs to build capacity for palliative care: Physical Skills Education (pain and symptom management for community-based nurses: Year 1) and ER Avoidance Education (chemotherapy/radiation therapy side effects management education; Year 2). In addition, in Year 1, Community Resource Education sessions were delivered to increase awareness of available community resources and services.
- 4. Nursing Guidelines for End-of-Life Care in Long-Term Care Settings Homes:** Training to support the implementation of EOL Care Nursing guidelines across all ESC Long-Term Care Homes.
- 5. Expansion of Video-Conferencing Capacity:** Development of video-conferencing sites to support education across the system, including training of in-house support for video-conferencing operation.

A comprehensive evaluation of the Education Blueprint was undertaken, examining both outcomes (summative evaluation) and development and implementation (formative evaluation). The evaluation report provides detailed information about the methods and results. This report focuses on the results of the evaluation of the Cultural Education component of the blueprint.

### EVALUATION METHODS

Evaluation objectives across all of the components of the Blueprint were aimed at:

- Providing feedback on planning/ training sessions
- Identifying impacts associated with education
- Describing the development and implementation of initiatives
- Describing progress to date

A mixed methods approach (quantitative and qualitative) was used to achieve the objectives of this evaluation. Sources of information included:

- Feedback surveys** completed by education participants to obtain reactions to the sessions (Volunteer training sessions, physical skills sessions, nursing guidelines for end-of-life care sessions); responses rates ranged from 73 -89%.

- **Follow-up surveys** to assess impacts of the education (physical skills, nursing guidelines for end-of-life care education programs); response rates ranged from 30-41%.
- **Individual and focus group interviews** with participants and managers (physical skills), managers to gather in-depth information on impacts and with initiative organizers to assess impacts and describe development and implementation (volunteer education, cultural education, expansion of videoconferencing capacity and the overall Blueprint initiative); in total 36 individuals participated in the evaluation interviews.

## KEY FINDINGS AND CONCLUSIONS

### Volunteer Education

- A total of 46 individuals participated in volunteer planning sessions; 51 individuals participated in various sessions aimed at volunteers.
- Training and information sessions (Hands on Care, Share the Care) were viewed positively; participants held favourable reactions to various aspects of these sessions including supporting resource material. Suggestions were made regarding improvements to delivery and potential topic areas for inclusion.
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- A partnership was formed with the Victoria Order of Nurses (VON) to deliver the Story-Telling Project; VON provided a coordinator to deliver the training and the Education Blueprint provided funding for resource materials.
- Cross-Sector Volunteer Planning sessions were well received; they were described as a significant opportunity for bringing all the sectors together to identify common needs, challenges, sharing of ideas, and solutions.
- Key impacts associated with the volunteer initiative have included: enhanced volunteer training, improved recruitment and retention, improved credibility of volunteers, and standardization of training and care.
- A number of factors were identified as facilitating the development and implementation of the volunteer training events: funding support, dedicated leadership and project management, and effective session facilitation. Challenges have included; tight timelines, lack of clarity/ understanding of in-kind contributions, limited follow-up support available, particularly for Share the Care, and limited local human resources to plan and prepare training events.
- Strategies for further implementation were suggested, including the need for clarity regarding in-kind contributions and continued opportunities for networking and planning.

**Conclusions:** The potential for enhanced training and concomitant enhancements to volunteer confidence, comfort, and performance are great. One of the most significant outcomes of this initiative has been the involvement of a broad range of stakeholders across sectors in the strategic planning of volunteer training in this region. Excitement was generated regarding the potential for shared training and resources as it was believed that this will have a significant impact on improvements to volunteer training across sectors and across the region. Further evaluation efforts might consider direct impacts of the training sessions on objective changes to volunteers practice (i.e., an examination of the ways in which volunteer work changes).

### Cultural Education

- Two meetings were held to develop relationships within the Walpole Island First Nation (WIFN) community and 15 members of this First Nation's community are currently participating in the Fundamentals of Hospice Palliative Care education program

(PPSMCP). Seven members of the WIFN community were individually interviewed to identify palliative care/ end-of-life care needs and gaps.

- A major accomplishment has been the development of relationships with Walpole Island First Nation leaders and health professionals. These relationships have facilitated the identification of the palliative care needs of the First Nation population, strategies to address these needs as part of the Education Blueprint and those that could be addressed through the PPSMCP.
- Introduction/ delivery of the Fundamentals of Hospice Palliative Care Education program on Walpole Island for PSWs represents a significant opportunity to fill an identified gap and is the first palliative care specific education program that has been delivered on Walpole Island. The availability of funding and support from Chief Joseph Gilbert were identified as facilitating the introduction of Blueprint organizers into this First Nation Community.
- Initiative specific and service delivery challenges were identified: time constraints, the slower pace of activity within the First Nation community, limited system capacity for palliative care and socioeconomic challenges that hinder optimal palliative care, and the cultural relevance of the Fundamentals program (content and delivery).
- Key to ongoing capacity building will be opportunities for exploring the relevance of the Fundamentals program for the WIFN community.
- Needs and gaps in palliative care within the WIFN community were identified specific to resources for institutional care (retirement home, LTC) and better supported home care.

**Conclusions:** Significant headway was made in establishing relationships with First Nation's leaders and health professionals on Walpole Island. This process of relationship building will take time and will be critical for continued support and sustainability. Resolution of the issues associated with the Fundamentals program will be important to developing the trust of the First Nation leaders and health care providers so that continued capacity building can occur.

### **Skill Specific Education**

- A total of 242 community-based frontline workers participated in the Physical Skills education program; 207 attended the Community Resources Education sessions.
- The Physical Skills sessions were well received by survey respondents; very few participants provided negative ratings and at least half of the respondents were able to identify changes to their knowledge and assessment and management skills.
- Interview participants described the Physical Skills sessions as largely review, particularly for those with previous palliative care education, and did not significantly impact practice change.
- The Community Resource Education session was described as most useful and the one in which participants learned the most "new" information.
- Overall, the sessions were described as a good opportunity to network with nurses from other agencies and share common experiences, challenges, and potential solutions, however, there were suggestions that this education did not need to be mandatory; it would have been preferable to target the Physical Skills sessions to new learners or to have basic and advanced levels to reflect existing capacity.
- Additional suggestions were made for improving the content, additional topic areas, learning supports and resources and the learning environment. Education delivered in conjunction with team meetings was a preferred format for delivery of education.

**Conclusions:** A number of positive impacts were associated with these sessions, including improved pain and symptom assessment and management and increased awareness of

available community support services. However, these perceptions were in contradiction of those managers and nurses who were interviewed; these individuals perceived that there was limited new information, thus they believed the sessions should not have been mandatory. Generally, there was much support for more palliative / end-of-life care education, for standardization of education, and ensuring that all community nurses are familiar with key palliative care concepts; both survey respondents and interview participants suggested additional topic areas that would be beneficial. Greater collaboration with the provider agencies around topic areas, scheduling, formats, and eligibility criteria may ensure greater “buy in” and support for future education.

### **Nursing Guidelines for End-of-Life Care in Long-Term Care Settings**

- The Nursing Guidelines for End-of-Life Care education program was delivered to 62 individuals representing 16 LTC homes in the region.
- The sessions were well received by survey respondents; ratings of various aspects of the sessions and the session leader were positive.
- The nursing guidelines were also well received; intuitively they make sense, create a common language and common goals for end-of-life care thus creating consistency in care (standardized care, provide direction for less experienced staff) and are easy to use.
- The guidelines are being used with most/ almost all residents or at least some residents who were at end-of-life. Some homes have not yet implemented the guidelines because of competing initiatives (e.g., the implementation of the MDS-RAI), but they have plans in place to do so in the near future.
- Key practice changes resulting from this initiative were related to use of the standardized tools (PPS, ESAS), use of the admission review check list, use of the EOL care pamphlet which has opened dialogue with family members, and increased knowledge regarding the signs and symptoms of impending death. Health system improvements include improved quality of care in long-term care, standardized end-of-life care, and improved communication among providers.

**Conclusions:** Overall, this education program was well received and positively evaluated by participants. The training assisted participants to change their practice/ use the nursing guidelines. Homes have been challenged to implement the guidelines and in-house training by time constraints and competing initiatives. However, the guidelines are viewed as a priority and many homes have plans in place to implement them in the near future. Many benefits (impacts) have been associated with the use of the guidelines; they have the potential to increase quality of life for residents and quality of end-of-life care in long-term care through the use of standardized assessment tools, provision of a common language with which to describe end of life, and development of consistent/ standardized care plans.

### **Expansion of Video-Conferencing Capacity**

- The expansion of video-conferencing capacity is currently in progress in two sites, one in Windsor, the other in Sarnia.
- A number of factors facilitated the development and implementation of this initiative including: Windsor Hospice’s history of providing education, existing network infrastructure (Windsor site), dedicated project management support, partnership and mentorship across sites and support at all levels (Blueprint and site-specific leadership, IT, OTN).
- Challenges to date have included delays created by technological issues, tight-time lines, and planning for installation in a building that is not yet built.
- Key lessons learned in the implementation of this initiative have included: the importance of utilizing existing experience and having basic IT support available, acknowledging that

installation takes time, the need to ensure equipment is compatible across the system, and planning for use.

- Strategies to sustain use were identified reflecting the importance of ongoing funding, champions, IT and administrative support, and promotion.

**Conclusions:** The major objective of this videoconferencing initiative was to have one site fully operational by the end of the first funding year. Technical delays external to and beyond the control of project organizers have prevented the achievement of this objective. Information and resource sharing between sites has facilitated implementation at the Sarnia site. This experience as well as additional lessons learned, particularly the importance of dedicated project management and technical support can be used to facilitate successful expansion across the region. Leveraging of existing infrastructures, particularly as related to technological supports will assist in the selection in additional sites. Although videoconferencing has yet to be utilized for education, there is much anticipation that it will greatly impact accessibility to education across sectors and across the region and that travel cost savings will be realized. Important strategies for ensuring sustained use of the equipment were identified in this evaluation. Strategies related to planning for marketing and promotion, identification of key champions for its use and availability of IT and administrative support will also be important to facilitating initial use and success. When operational, opportunities to gather feedback from users on technology performance (sound and picture quality), satisfaction, comfort, benefits, and suggestions for improvement can be used to inform further development and implementation of this initiative.

### **Evaluation of the Overall Education Blueprint**

- Across all of the initiatives of the Education Blueprint, various information, education, and planning sessions were delivered with 581 individuals in attendance.
- Development and implementation of the blueprint were facilitated by: existing information on education needs and gaps; existing and new infrastructure; financial support; effective leadership, and good communication, support at all levels; project management support and forced deadlines.
- Challenges to implementation included: short timelines, lack of existing infrastructure, relationships and champions in some areas, technological and personnel issues impeding completion of the video-conferencing initiative, competing projects, nursing layoffs, and limited cross-sector involvement.
- Key lessons learned that will assist with continued implementation have highlighted the importance of champions, funding commitment, dedicated human resources, support at all levels, networking and partnerships, leveraging existing structures, effective communication strategies, and evaluation.
- Suggestions for improvements and further implementation of the blueprint included: better admin support and financial accounting system, continued leveraging of programs and the need for: increased cross county and sector collaboration, more skill specific education, strategies to ensure knowledge transfer, greater emphasis on a systems-level approach, continued leadership and promotion and the need to clarify responsibilities regarding in-kind contributions.
- Although the short time makes it difficult to demonstrate improved competency at a system level, early impacts were identified related improved quality of care, increased access to palliative care education and capacity building for health care providers and volunteers, enhanced relationships/ partnerships for education, improved coordination and integration of education; increased participation of the volunteer sector and increased awareness of palliative care issues across the system.

**CONCLUSIONS:** Based the results of this evaluation the following conclusions can be made:

- The ESC EOLCN Education Blueprint has accomplished a great deal in a short period of time. Overall objectives were largely achieved and those that were not were beyond the control of Blueprint organizers (e.g., technological delays with the videoconferencing installation). A number of important training/ education programs were held for volunteers and frontline workers in the community and long-term sectors. The sessions were generally well attended and well received. Although there were some challenges experienced in implementing these initiatives, some unique to the specific programs (e.g., the mandatory nature of the Skills Specific sessions) and others common across all program (e.g., tight lines, competing priorities), changes in practice and benefits to care recipients and their families, care providers and the health system were identified. Major achievements identified across the initiatives of the Blueprint highlight the support for more palliative / end-of-life education in this region and the importance of relationship and partnership building, opportunities for networking across sectors and across the region to share ideas and resources, and inclusion of all key stakeholders in planning and decision making in order to maximize education strategies, including leveraging existing infrastructure and resources for capacity building.
- The need for enhanced palliative care is well documented in the published literature and there is much support for education as a strategy to improve care. The initiatives of the Education Blueprint have the potential to have a significant impact on palliative care across the region. The Blueprint provides an opportunity to provide a coordinated, integrated, and standardized approach to education. This type of approach to palliative care education is unprecedented in southwestern Ontario, and most likely the entire province. This evaluation has identified a number of important and practical strategies for sustainability and further development, many of which will further enhance education efforts (e.g., planning for shared implementation of volunteer education, exploring how existing education programs meet the needs of the WIFN learners, building skill specific education on existing capacity, mentorship support for ensuring practice change and greater inclusion of the long-term care, complex continuing care, and acute care sectors). Increasing capacity for palliative care across the continuum of care by ensuring the consistent use of assessment tools, common language, and care models will serve to support and enhance other initiatives of the ESC EOLCN aimed at enhancing palliative care (e.g., the expansion of Palliative Consultation Teams across the region).
- This evaluation identified many factors that facilitated and challenged the development and implementation of education programs. Attention to these factors as well as identified lessons learned will serve to inform and maximize education efforts going into Year 2 of this initiative. Similarly, this evaluation identified factors that facilitated and challenged application of education to clinical practice. Attention to these factors as well as strategies identified by evaluation participants to support knowledge transfer (e.g., resource materials, mentorship and follow-up support) will also serve to support education efforts going into Year 2.

**Evaluation Limitations:** The identified impacts associated with the training provided as part of the Education Blueprint were largely self-reported by key stakeholders and anecdotal; objective measures of impacts (i.e., performance/ outcome indicators providing empirical evidence of practice changes and impacts) while difficult to develop would provide validation of the qualitative data generated by this evaluation.

# Cultural Education

## Executive Summary: Cultural Education

**Introduction:** The Year I activities of this component of the ESC EOLCN Education Blueprint were aimed primarily at working with Walpole Island First Nation representatives to identify their palliative care needs and develop strategies to meet identified needs of health care providers working within the First Nation's community.

**Evaluation Methods:** The evaluation objectives of the Walpole Island First Nation (WIFN) education initiative were to: i) describe the development and implementation of this initiative and, ii) describe existing gaps and needs for optimal palliative care service delivery in this community. **Focus group and individual interviews** were conducted with leaders from the First Nation's community and individuals involved in developing the Education Blueprint and with various health professionals working within the First Nations community.

### Key Findings

**A major accomplishment** has been the development of relationships with WIFN's leaders and health professionals. These relationships have facilitated the identification of the palliative care needs of their First Nation population, strategies to address these needs as part of Education Blueprint and those that could be addressed through the PPSMCP. Introduction/ delivery of the Fundamentals of Hospice Palliative Care Education program on Walpole Island for PSWs was viewed as a major accomplishment as it represents a significant opportunity to fill an identified gap and is the first palliative care specific education program that has been delivered to this group of frontline workers.

**Facilitating Factors:** The availability of funding and support from Chief Joseph Gilbert were identified as facilitating the introduction of Blueprint organizers into the WIFN community.

**Challenges:** Initiative specific and service delivery challenges were identified: time constraints, the slower pace of activity within the First Nations community and limited system capacity for palliative care and socioeconomic challenges that hinder optimal palliative care on Walpole Island and some initial concerns of the relevance of the Fundamentals program to the WIFN community; strategies are in place to address these concerns.

**Sustainability strategies:** Key to ongoing capacity building will be opportunities for exploring the relevance of the Fundamentals program for front-line workers in the WIFN community..

**Needs and Gaps:** Needs and gaps in palliative care within the WIFN community were identified specific to resources for institutional care (retirement home, LTC) and better supported home care.

**Conclusions:** Significant headway was made in establishing relationships with Walpole Island First Nation leaders and health professionals. This process of developing these relationships, while slow, will be critical for continued support and sustainability.

## 1.0 Introduction

This component of the ESC EOLCN Education Blueprint was aimed at the development of training and policies and procedures sensitive to the needs of First Nation populations across all sectors. Year 1 activities were aimed primarily at working with Walpole Island First Nation representatives (elders) to identify the palliative care needs of this community and to assess

the needs of health care providers working within the First Nations community. Early in this process it was noted that more palliative/ end-of-life care education was needed for front-line workers on Walpole Island. To meet this identified need immediately, the Fundamentals of Hospice Palliative Care education was delivered by the PPSMCP on Walpole Island, lead by an experienced facilitator; 15 care providers are registered in this program. (evaluation this latter initiative is not a component of this evaluation).

**Planning Activities:** Representatives of the Education Blueprint (Julie Johnston, and Maura Purdon, Project Manager) met with Walpole Island First Nation Leaders (Chief Joseph Gilbert, Rev. Paul McPhail) on two occasions to discuss the Walpole Island First Nation's needs for palliative care education, existing gaps in service and opportunities to enhance palliative care within this community.

## 2.0 Evaluation Objectives and methods

**Evaluation Objectives:** The evaluation objectives of the First Nations education initiative were to:

- i) describe the development and implementation of this initiative:
  - What are the lessons learned in the development and implementation of this initiative (i.e., relationship building with First Nations leaders)?
  - What are suggestions for improvement? For sustainability? For expansion to other counties?
  - What are potential next steps for this initiative?
  - What are the potential impacts of this initiative (for the First Nations population, care providers, and for the health system)?
- ii) describe existing gaps and needs for optimal palliative care service delivery in this community:
  - What are their perceptions of existing gaps in palliative care service delivery?
  - What do they need (human and physical resources) to provide optimal palliative care in this community?
  - What suggestions do they have for service delivery improvement?
  - What goals, visions, dreams do participants have for palliative care service delivery?
  - How would they like to be involved in resolving existing education/care gaps?

Evaluation information will be used to inform further development and implementation of this initiative, including supports and resources needed to maximize success.

**Source of Information:** To meet the above evaluation objectives the following sources of information were employed:

**Focus Group and Individual Interviews with Initiative Organizers:** Individuals involved in the development and implementation of this initiative were invited to participate in interviews to obtain in-depth information about the development and implementation of this initiative (as described above). The interview guide (presented in Appendix A) was distributed to participants prior to the interview for review.

A focus group interview was conducted with 6 individuals on April 6, 2009 in person at First Nation's Band office on Walpole Island. In attendance were leaders from the WIFN community (4) and individuals involved in developing the Education Blueprint (2). This interview was 90 minutes in length. An additional, individual interview was conducted with an Education Blueprint representative; this interview was 22 minutes in length.

**Individual Interview with Health Care Professionals and Community Members:** Health care professionals (N = 3; working within the WIFN community and other community members (N = 4, representing Pastoral Care, Education, the Walpole Island Band government) were invited to participate in individual interviews to obtain in-depth information about existing care gaps and needs for supports and resources to enhance care. The guide for these interviews is presented in Appendix B.

These interviews were conducted by a member of the WIFN community. Interviews were conducted in person with 7 individuals on Walpole Island; they ranged in length from 60 – 90 minutes.

**Data Collection and Analysis:** The evaluation consultant conducted the focus group interviews, which were audio-recorded and transcribed. Interview data analysis was consistent with recommended practices for qualitative data.<sup>1</sup> The focus group interviews with health professionals was conducted and summarized by a member of the WIFN community (Health Care Provider).

### 3.0 Results

The following is a summary of the highlights and main themes that emerged from the interviews with initiative organizers and WIFN leaders and health care professionals working within the First Nations community.

#### 3.1 Objective I: Describe the development and Implementation of this initiative

**Major accomplishments:** Key stakeholders identified a number of significant accomplishments to date related to this initiative. A key accomplishment has been the development of relationships with WIFN leaders, specifically Chief Joseph Gilbert and key health professionals. These relationships have facilitated the identification of the palliative care needs of the WIFN population, strategies to address these needs within the limited funding available as part of the Education Blueprint for this initiative and the identification of needs that could be addressed through the PPSMCP. Introduction/ delivery of the Fundamentals of Hospice Palliative Care Education program on Walpole Island for PSWs was viewed as a major accomplishment as it represents a significant opportunity to fill an identified gap and is the first palliative care specific education program that has been delivered to this group of frontline workers.

*"I think it was a great process. It was one we'll continue to build on. This [Fundamentals education] is one of many spin offs we'll have....we'll build on these relationships for years to come."* [Project Organizer]

**Facilitating Factors:** The availability of funding was identified as key facilitating factor for this initiative, as without it inclusion of the First Nation community in the Blueprint would not have

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<sup>1</sup> Patton, M.Q. (2002). *Qualitative Evaluation and Research*. Thousand Oaks, CA: Sage.

been possible. Support from Chief Joseph Gilbert facilitated introduction of Blueprint organizers into the First Nation Community.

*“Chief Gilbert really facilitated our introduction in the First Nation, paving the way with his endorsement and support.” [Project Organizer]*

**Challenges:** A number of challenges to date with this initiative specifically and with palliative care service delivery on Walpole Island were identified:

- **Time constraints:** There was a short period of time within which to establish relationships and move forward on initiative objectives. Historically the WIFN community has had difficulty trusting outsiders who want to create change on Walpole Island. Project organizers had hoped to accomplish much more within the allotted time frame but needed to acknowledge that relationship/ trust building with the WIFN community would take than they had anticipated and as a result they would need to modify their first year objectives for this initiative.
- **Cultural Uniqueness:** It was noted that there are cultural differences in pace of activity. In contrast culture of the project organizers, the pace of activity within the First Nations community is much slower.

*“The pace is different. Culturally we move more quickly. Their pace is much slower. We learned quite soon that we needed to adapt.” [Project Organizer]*

- **Significant palliative care related gaps:** There is currently no formal education available for hospice palliative care on the Walpole Island. System gaps also exist related to limited facilities for elder care and limited system capacity for palliative care.

*“One of [First Nations] goals, what they would really like to see is a long-term care facility on Walpole Island. But even if they had one, they don’t have human resources with skills and knowledge in hospice palliative care to staff a long-term care home.” [Project Organizer]*

- **Socioeconomic challenges:** It was noted by First Nations leaders that in order for palliative care initiatives to be successful on Walpole Island, project organizers will need to understand the context in which the First Nations community lives. High rates of mortality, unemployment, drug and alcohol abuse, criminal activity, poverty, ongoing emotional distress resulting from residential school abuses, and no financial assistance to obtain treatment off the Island (reimbursement/ tax benefits for travel) challenge families to provide palliative/ end-of-life care for their loved ones.

*“We are happy that we can talk to you about these things [socioeconomic challenges]... You really need to work with these things and understand the depth of the grief here.” [FN representative]*

It was noted that limited resources prevent the First Nation’s people from building capacity for palliative care. Beyond expert resources, they lack the resources needed to deliver education programs, such as space, funds for refreshments, and funds for compensation/ staff coverage for attendance. Understanding these issues will be critical for developing strategies to effectively meet the needs of this community.

- **Limited cultural relevance of the Fundamentals program:** It was noted that the Fundamentals program (2 sessions held to date at the time of the evaluation interview) has not been well received by participants because it is not culturally relevant. For example some of the questions being asked about symptom management and death do not make sense from their cultural perspective. Learning strategies are also not consistent with how First Nations people typically learn – story telling is a strong component of their learning so that the written materials and didactic (lecture) components are not effective.

*“We have a different way of learning here. They’ll [participants] learn more from story telling and sharing than text communication.... First Nations people won’t tell you openly when they don’t understand something.” [FN representative]*

*“When First Nations people leave Walpole Island to take courses they switch to a Western mode, but when on Walpole Island you have to use a First Nation mode of learning.” [FN representative]*

Moreover, it was noted the First Nation community has a history of negative experiences of outsiders attempting to implement “Western society” programs with little input from the First Nations peoples.

*“The government thinks that they can come in here and do their programs. They think that the people here should adapt to the program but that’s not going to happen. Program need to adapt to the culture. The culture is not going to adapt to the program.” [FN representative]*

**Sustainability strategies:** Project organizers noted that they intend to remain involved with the WIFN community keeping their leaders engaged and developing a transparent plan for capacity building on Walpole Island. It was noted that critical to their ongoing success is their ability to deliver what they promise. It was noted that First Nation’s people have a philosophy of “Bi-maad-zin-win”, meaning ‘full life’, ‘good life’. Within this philosophy the First Nation’s people celebrate their history and unique contributions within their community. Key to success will be opportunities for exploring the relevance of the Fundamentals program to front-line workers within the WIFN community. The PPSMCP has developed a plan for exploring how existing palliative care education programs are relevant for the WIFN community.

**Next Steps:** The results of the focus group interview with First Nations health care providers will be used to further inform planning to meet their needs. An extra session has been added to the Fundamentals program as an opportunity to further explore relevant cultural issues. These findings will be compared with the PPSMCP’s learnings from their involvement with the Oneida Band to learn more about how specific cultural needs can be met.

### 3.2 Objective II: Palliative Care Needs and Gaps

A report on the palliative care needs and gaps (arising from the interviews with health professionals and WIFN community members) is presented in Appendix C.<sup>2</sup> Key themes arising from this report include:

- The cultural uniqueness of the First Nation’s peoples with respect to palliative care issues (e.g., suffering, illness, death, and grieving).

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<sup>2</sup> This report was prepared by: Charlene Dodge, Jane McFadden, and Maura Purdon.

- Socioeconomic issues impacting health such a poverty, limited access to health care expertise, environmental issues, spiritual despair.
- There are key resources needed for palliative care: physical space (retirement home/ LTC home/ palliative care facility and home care support for those dying and support (education, supportive resources) for care providers.
- The WIFN community is challenged to provide optimal palliative care to their members by: limited resources to support home care, limited access to palliative / end-of-life care due to limited transportation, limited education/ training among First Nations peoples, and limited funding.
- The need for additional education was identified related to family caring, use of medical equipment, grief training, drug and non-drug interventions, and 'hands on' training for PSWs and HSWs. Generally there is a need for more First Nation's people who are trained health care professionals.
- A number of potential next steps were articulated including the implementation of a more comprehensive needs assessment that would inform proposals for funding to meet specific needs related to institutional care (retirement home, LTC) and better supported home care.

#### **4.0 Conclusions**

Based on the results of this evaluation the following conclusions can be made:

- Significant headway was made in establishing relationships with WIFN leaders and health professionals. This process of developing these relationships, while slow, will be critical for continued support and sustainability.
- The WIFN community is experiencing a number of significant socioeconomic challenges which impedes their ability to build their capacity for palliative / end-of-life care. While they are thankful for the opportunity to increase the knowledge and skills of their front line workers, it is clear that they will need an education strategy that is culturally relevant and delivered in a way that is consistent with the way they live and learn. Acknowledging existing challenges with the delivery of the Fundamentals of Hospice Palliative Care Education program, project organizers have been proactive in developing exploring potential revisions to the program to make it more relevant to the learners. First Nations leaders are satisfied that projects organizers understand the issues at hand and are working with participants to rectify the challenges. Resolution of these issues will be important to developing the trust of the Walpole Island First Nation leaders and health care providers so that continued capacity building can occur.

## Acknowledgements

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## Guide for the Interview with First Nation's Initiative Organizers

The purpose of this interview is to gather in-depth information from the core group involved in developing/ planning this initiative.

### **Development/ Planning**

- What do you think were some of the major accomplishments to date with this initiative?
- What factors facilitated the development/ planning for this initiative?
- What were some of the challenges experienced and how can these be overcome in future endeavours?
- What additional supports or resources are needed to make this initiative successful?
- What are some of the key lessons learned to date from this initiative?
- What did you learn about the key gaps and needs related to palliative / end-of-life care education in this region?
- What suggestions do you have for improving/ sustaining the gains/ relationships made to date?
- What are the next steps for this initiative?

### **Potential Impact:**

- If this initiative is implemented as planned, what do you think are the potential impacts/ outcomes for the First Nation's community?
  - What are the potential impacts for care providers?
  - For the health system?

### **Additional Comments**

Do you have any additional comments that you would like to make about this initiative?

## Guide for the Interviews Walpole Island First Nation Community Members

### Background and Purpose

The Erie St. Clair Local Health Integration Network (LHIN) received funding from the Ministry of Health and Long-term Care under the Aging at Home Strategy to develop a framework or 'Blueprint' for education focused on the development of an Erie St. Clair wide, integrated, cross-sector hospice palliative care education program. Part of the funding is targeted at deepening the understanding of cultural practices, norms, gaps and challenges around hospice palliative / end-of-life care and service delivery. The Erie St. Clair End-of-Life Care Network is pleased to be working in partnership with the Walpole Island First Nation community to deepen the understanding of hospice palliative / end-of-life care in First Nation communities with the goal of improving palliative / end-of-life care.

The purpose of this interview is to gather in-depth information from *community members and health care providers* about existing gaps, needs and challenges associated with palliative care/end-of-life care service delivery in the Walpole Island First Nation community.

### Education and Care Gaps

- What are some of the **challenges** experienced in providing or receiving palliative / end-of-life care within the Walpole Island First Nation community?
- What **gaps** in palliative care service delivery **currently** exist?
- Do you have any **suggestions for filling these gaps**, or improvements to palliative / end-of-life care service delivery?
- What do you **need**, in terms of both human and physical resources, in order to provide better palliative care within or to the Walpole Island community?
- What are the **education needs** of health care providers providing palliative / end-of-life care within the Walpole Island First Nation Community?
- What **goals, visions, and dreams** do you have for palliative care service delivery within the Walpole Island community?
- Do you have any **suggestions** for how these visions can be achieved?
- As you know, the Erie St. Clair End-of-Life Care Network is interested in assisting First Nation communities to enhance the quality of palliative / end-of-life care provided to First Nation community members through the development and implementation of education and training initiatives specific to First Nation people. **Who** do you think are the key individuals who should be involved in developing and implementing education initiatives within the First Nation community?

- Would **you** be interested in being involved in resolving existing education/care gaps?
- **How** would you like to be involved?

### **Additional Comments**

Do you have any **additional comments** that you would like to make about education/ care gaps within the Walpole Island or broader First Nations' communities?

### Walpole Island First Nation Palliative Care Education Needs and Gaps Report Report Prepared by: Charlene Dodge, Jane McFadden, and Maura Purdon

#### Background and Purpose

The Erie St. Clair Local Health Integration Network (LHIN) received funding from the Ministry of Health and Long-term Care under the Aging at Home Strategy to develop a framework or 'Blueprint' for education focused on the development of an Erie St. Clair wide, integrated, cross-sector hospice palliative care education program. Part of the funding was targeted at deepening understanding of cultural practices, norms, gaps and challenges around hospice palliative and end-of-life care and service delivery across culturally diverse groups.

The purpose of the Walpole Island First Nation (WIFN) Palliative Care Education Needs and Gaps Survey was twofold;

1. To gather in-depth information from a small number of *community members and health care providers* about existing gaps, needs and challenges associated with palliative/end-of-life care service delivery in the Walpole Island First Nation community.
2. To use survey learnings as input into recommended direction and funding support for Year Two of the Erie St. Clair Hospice Palliative Care Education Blueprint projects (2009/2010).

This 'Needs and Gaps Survey Summary' incorporates findings from the WIFN March 2009 survey, documentation from meetings with Chief Gilbert and Walpole Island Community and Health Care staff as well as resource information provided by Jane McFadden, Walpole Island Nurse Case Manager.

The 'Needs and Gaps' survey was designed by an external Evaluation consultant then discussed and revised based on input from WIFN. Individual interviews were conducted and responses documented in March 2009 by a WIFN Community Worker. All interviews were based on a standardized set of Survey questions.

Seven WIFN Community members or health care providers were interviewed; 5 women and 2 men. Each 1-1 interview was 1-1.5 hours in length. Respondents ranged in age from 38 to 83 years and came from diverse backgrounds including Primary Health Care, Pastoral Care, Education, Social Work and Walpole Island Band government. Two respondents were retirees. Three are currently employed in Health Care. Five of the seven people surveyed reported personal experience in providing palliative care.

In April 2009, following completion of the interviews, a Draft Survey Summary document was developed. The Draft document was reviewed by members of the WIFN Working Group late April and this final Summary document developed based on WIFN feedback.

### **Walpole Island First Nation Community<sup>3</sup>**

The traditional name of the community is Bkejwanong. Walpole Island is unceded aboriginal territory occupied by Ojibwa, Pottawattomi & Odawa Nations. The Nations share language, traditions & political cohesion. Together they form what is known as the Council of Three Fires or the Three Fires Confederacy.

Walpole Island is located on the delta islands of the St. Clair River. There are 6 islands in total, 2 are inhabited. The "Island" has a unique ecosystem; 6,900 hectares of the richest & most diverse wetlands in all of the Great Lakes.

The WIFN community numbers about 2,179 people on the reserve and another 2,000 Band members off reserve. Citizens of WIFN can still support their families through hunting, fishing, trapping, and guiding activities. The number one industry in the community is recreation and tourism.

Community membership is made up of First Nations people who have lived in this territory for many generations, some dating back hundreds of years prior to colonization. The community has a long association with the land, water and each other.

The age profile of Walpole Island First Nation, when compared to the Ontario non-native population, is that of a much younger community with a slightly lower percentage of middle aged people and a significantly lower number of people over

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<sup>3</sup>Community information from WIFN Heritage Centre website and Band resource documents provided by WIFN Nurse Case Manager, March 2009.

age 65. Far more WIFN members over age 65 live alone than is the norm for the Ontario Non-Native population. Large families are common. The number of single parent families is 3 times higher than the number in the Ontario Non-Native population. Like many reserves the community struggles with a crime and addiction issues.

There is an elementary school on Walpole Island and a strong local commitment to education. Secondary and post-secondary education is accessed off-reserve. The community has a Library, Arena and Heritage Centre.

Several traditional native spirituality sects are active in the community. There are 4 ‘on-reserve’ churches; United, Anglican, Pentecostal and Fundamentalist denominations. Some community members hold combinations of Christianity and traditional native beliefs.

Walpole Island First Nation is led by a Chief and 12 Council Members. The community has a volunteer fire department and local police force primarily staffed by native personnel. A new water treatment facility was built in 2008. There is no sewage infrastructure but each home has an in-ground septic system.

### **Walpole Island First Nation Culture<sup>4</sup>**

Although comments on culture need to be considered with caution as traditions and norms vary considerably within and across First Nation groups, seven cultural characteristics emerged from the interviews and meetings held with Walpole Island First Nation members;

1. A strong desire to die at home or, if not able to die at home, to die in a WIFN community facility. The desire to die at home was seen by respondents as related to a strong historical connection to the land and water...”when we are not home on our reserve we feel disconnected.”
2. A cultural way of dealing with suffering, death and illness. One community member noted that “wakes are held in the WIFN community at homes not funeral parlours.” The community comes together to support the family of the deceased.

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<sup>4</sup> Information in this section from March 2009 1-1 interviews, December 2008 meeting with Chief Gilbert and Band resource documents provided by the WIFN Nurse Case Manager, March 2009.

3. In the WIFN community, large families are the norm as is visiting for long periods of time. The cultural expectation is that a lot of time will be spent with the seriously ill or dying by members of the family, loved ones and community members.
4. Traditionally, health is viewed holistically by First Nations people – mentally, physically, spiritually and emotionally. Today, although the elders still teach about the importance of having a holistic view of the person, the capacity of First Nations communities to plan for future needs has been adversely affected by the results of centuries of colonization and the disempowerment of First Nation people.
5. The WIFN community struggles with the effects of colonization include poverty, isolation, addictions, violence and depression. Added to these are the long term intergenerational effects of residential school placement, a system which fractured families, erased culture and contributed heavily to the ongoing grief reaction and dysfunctional family relationships often seen in First Nation communities. WIFN Church Leaders and Traditional Healers have been actively working for the past 3 years on community healing.
6. There is strong respect for Elders and power/respect for the Grandmothers.
7. There is local support if someone wants to go into Medicine/Health Care. There are Walpole Island First Nation medical professionals currently practicing in Canada and the United States.

### **Factors Affecting Health of Walpole Island First Nation Community**

A number of factors are viewed as impacting the health of the WIFN community. Some of the factors below were articulated by WIFN survey respondents. Other factors were noted in meetings with community staff or WIFN Band documentation.

- **Poverty** – As many as 50% of the families in the community may be in receipt of income security at any given time. This statistic does not include the number of people receiving Ontario Disability Support or Old Age Pension or other government transfer payments. Discretionary income is low and unemployment high.

- **Transportation and Health Care Facility Access:** Within the WIFN community there is a 3 part health system comprised of health promotion & prevention, addiction prevention and home care. Primary care is not available in the community and must be accessed from clinics, doctor's offices and emergency rooms within a 60 kilometre radius. There is no public transportation system in place to enable WIFN members to access health care. Many WIFN members have neither a car nor the income to hire a taxi.
- **Access to Health Care Expertise:** A historical paucity of family doctors, combined with a natural reticence to seek medical services off reserve has resulted in a large percentage of "orphan" patients, or people unattached to a specific family doctor with implications for early detection, diagnosis and treatment.
- **Environmental:** There is concern for local water quality and long term health impact related to a number of factors including upstream chemical releases.
- **Physical/mental health:** It was not within scope of this project to undertake specific research on the health of WIFN people however the literature on the health of First Nations people is well documented. In discussion with local Health Care providers the local WIFN picture is not at odds with the national picture. The figures below are from Health Canada and Statistics Canada documents for 2005 and 2000 respectively;
  - Reduced life expectancy for both men and women relative to Canadian Non-Native population
  - 3X's the Canadian rate of diabetes
  - Alcohol related deaths between 4 and 9 times higher
  - Drug-induced deaths up to seven times higher
  - Compared with the overall Canadian population, First Nations had higher rates of pertussis (2.2 times higher), rubella (7 times higher), TB (6 times higher), and shigellosis (2.1 times higher)
  - Higher rates of mental illness
- **Housing, Education and Crime:** Housing on WIFN is of mixed quality. The crime rate is a concern.

- **Spiritual despair and Intergenerational impact of residential schools:** Related to the historical trauma & ongoing effects of colonization and the misunderstandings of natives by non-native people including racism. Despair is often expressed in unresolved grief, depression, family breakdown, addictions and, vandalism. In discussion with members of the Health community the emotional weight of continual loss was clearly a concern. This is a small, closely knit community. Any new loss has the potential to impact the community as a whole with the impact magnified by the long history of deep loss.

### **Walpole Island First Nations Health Programs and Services**

Walpole Island has 3 Health Programs. The Community Health Services Program was put in place more than 25 years ago. It acts to educate the community about health issues, seeking to build capacity within the individual community member to make healthy lifestyle choices to prevent disease. The Native Alcohol and Drug Abuse Prevention Program (NAADAP) was initiated soon after the Community Health Service Program, with promotion and prevention of these harmful substances as its mandate. The third and most recent program, Home & Community Care, was put in place in 2001 with the goal of building bridges between the health care system and the native population. The HCCP program also offers nursing, case management and client advocacy.

Primary care is not available in the community, but must be accessed from clinics, doctor's offices and emergency rooms within a 60 kilometre radius. Ambulances are off reserve. Houses are not given numbered addresses. Detailed and highly descriptive directions are necessary when calling for an ambulance. There are no 911 emergency numbers.

The reserve is supported by a Nurse Case Manager hired by the Band and reporting to the Chief and Council. The duties of the Nurse Case Manager include;

- Case management, referrals, linkages and client advocacy
- Assistance with medication and treatment approvals with NIHB, Ontario Works
- Hospital Liaison Duties
- Home Care Nurse, Professional Development and Continuous Learning

- Teaching health professionals culturally sensitive care
- Teaching/delegation of nursing acts to unregulated health professionals

## **Goals, Visions & Dreams for Walpole Island First Nation Palliative & End-of-Life Care**

Survey respondents showed a high degree of similarity in their response to the question “What **goals, visions, and dreams** do you have for palliative care service delivery within the Walpole Island community? “

Responses centred around **two** areas, facilities and support/service;

1. Retirement/Palliative Care facility on Walpole Island staffed by trained First Nations people providing 24/7 care.
2. Compassionate care, comfort and dignity for the seriously ill and dying; appropriate support, including education, for those caring for the dying.

## **What’s Working Well Today in Palliative and End-of-Life Care?**

While there was no specific survey question on ‘what’s working well’ a number of people made comments on things that were working well.

Generally support from within the community was viewed positively. Specific comments are listed below;

- Support from within community can work well; no travel distance and everyone knows how to reach one another.
- Home Support, VON, HCC program all provide excellent support for the seriously ill and dying.
- Various program groups work well together to manage need/s.
- Care givers are very kind when working with the seriously ill.
- There is a full time Walpole Island Nurse Case Manager who reports to Band and is trusted by, and understands, WIFN and the broader community.
- Generally, community very responsive to need.

## **Key Challenges in Palliative and End-of-Life Care?**

Several questions on the survey asked about challenges in palliative and end-of-life care. Responses can be grouped into 6 broad buckets;

1. Managing HPC care at home in the WIFN community
2. Accessing quality and timely HPC and EOLC treatment outside of WIFN
3. Supporting care when ill person needs care outside of WIFN
4. Education and Training
5. Funding and Income
6. Diversity in Spiritual Beliefs and Practices across WIFN Community

Within each broad bucket there were a number of different challenges suggesting a range of possible solutions. Respondents were not asked to set a priority on which challenge was the greatest however 3 themes surfaced constantly;

1. Lack of a WIFN facility like a Retirement Home where the seriously ill could go when they were unable to manage at home.
2. Lack of respite care/support for the family in managing seriously ill people at home couple with lack of understanding by family as to how to provide care at home.
3. Lack of transportation to enable community members to get medical care or treatment or to provide support for the care of others outside of WIFN.

A more detailed breakdown of the challenges under each of the 6 broad buckets is outlined below.

- **Managing HPC care ‘at home’ in the WIFN community**
  - Lack of sufficient funding for necessary ‘at home’ support (PSWs and HSWs).
  - Lack of HPC education and training for ill person, families and caregivers managing care at home. Families lack training in how to care for very ill and dying.
  - Lack of equipment to support ‘at home’ care e.g. hospital beds, lifts.
  - Caregiver fatigue a concern; lots of single parents and not everyone has a large family to help with care.
  - 24/7 medical support only available outside of WIFN. No ‘night’ or ‘weekend’ respite support on Walpole Island.

- **Accessing quality and timely HPC and EOLC treatment outside of WIFN**
  - Travel costly and difficult. Many WIFN community members do not have cars.
  - Can be difficult to arrange child coverage where only one parent managing household.
  - Lack of understanding/acceptance of cultural traditions and practices around death and dying by non Native community. Challenge integrating traditional spiritual beliefs and practices into care. Culture of ‘visiting’ a part of FN way of supporting dying people.
  - Strong cultural preference to ‘die at home’ in WIFN community. Having to go ‘off Island’ at odds with what WIFN people would prefer.
  - Many WIFN community members do not have a family physician. Serious, longstanding shortage of physicians in the area to provide frontline care.
  
- **Supporting care when ill person requires care outside of WIFN**
  - No public transit. Costly to have to use a taxi if no car available. Many WIFN community members do not have cars. Impact is fewer visits/ less family and community support for the seriously ill person.
  - Increased feeling of isolation. Loss of connection for the seriously ill person with the community, land, water and First Nation cultural traditions.
  
- **Education and Training**
  - WIFN people lack training in HPC and EOL care. Insufficient number of trained FN staff to deliver care primarily by FN people.
  - Community/family members not knowledgeable about wills, palliative care plans, DNR’s, medical coverage.
  - Community members returning to die ‘at home’ may have unrealistic expectations as to the level of care that the community can provide.
  
- **Funding and Income**
  - Dollars not available to purchase additional care or support for care in the home e.g. pay for more time from PSWs or HSWs, pay for necessary equipment or modification of facilities, improve wages, offer 24/7 support.

- Income levels for WIFN community are generally low. Dollars not available to purchase additional medical coverage, equipment for the home, etc.
- **Diversity in Spiritual Beliefs and Practices across WIFN Community**
  - Sometimes there is conflict between Traditional and Christian beliefs and practices around death and dying. Survey respondents noted that both Traditional Healers and Christian Spiritual people need to be involved in HPC and EOL care.

### **Additional Gaps in Palliative and End-of-Life Care?**

The survey also asked people to comment on gaps in palliative and end-of-life care. Some of the responses mirrored responses to the question on challenges but there were some additional gap areas;

- No Retirement Home/Chronic care facility on Walpole Island. Community members must seek treatment off the reserve.
- No apartments for elderly when they can no longer manage at home.
- 24/7 hour care not available on WIFN when it is needed.
- Elderly in community need help in cutting grass in summer and snow removal in winter; need help on small household repairs.
- Not enough communication between main stream health system/hospital and WIFN community.
- Not enough trained staff including Nurses, PSWs and HSWs. Community needs more medical support.
- Decentralized service can be a problem when replacement equipment is not available on Walpole Island.
- Presently, alternative therapies like massage, therapeutic touch are not available to community members.

- There is no Funeral Home on Walpole Island.

### **Areas Where Palliative or End-of-Life Care Education is Needed**

Survey respondents were asked to specifically focus on the areas where they felt more palliative or end-of-life care **education** was needed. Again, some of the responses were similar to comments made under the questions on gaps or challenges but some additional responses emerged as well. The list below outlines some of the additional responses. Order is not indicative of priority need;

- Grief training.
- Palliative Care training including training for families on what to expect when caring for the dying, how to care for the very sick & how to manage self e.g. caregiver fatigue.
- First Nations people trained as doctors, registered nurses, practical nurses, Physical Therapists, Occupational Therapists, foot doctors, counselors, psychiatrists, clerks, administrators. WIFN people trained to support VON and other outside agencies.
- People trained on how to use medical equipment e.g. lifts.
- Family members and care givers trained on side effects of drugs/narcotics as well as training on mouth care and Therapeutic Touch.
- Training on where to go to get equipment and record of who paid for equipment.
- Deeper HPC and EOLC training for workers including ‘hands-on’ training for PSW and HSW workers.

### **Closing Gaps, Meeting Needs & Managing Challenges: Possible Next Steps**

Finally, survey respondents were asked to identify actions or steps to help close gaps, meet needs or manage challenges. A number of ideas were suggested by respondents. The ideas have been grouped under separate headings below. The steps range from some that could be done fairly quickly, over the short term, to some that would be significant undertakings and require longer planning and far more funding. Respondents were not asked to prioritize one action over another but it should be noted that most respondents;

- Identified the need for some kind of Seniors, Nursing. or Retirement/Palliative Care facility on Walpole Island.
- Spoke about the need for more home support of one kind or another; several thought that having available 24/7 support for end-of-life care was critical.
- Noted that more funding was needed for better end-of-life care.

Everyone interviewed noted the importance of having trained First Nations people working in the Walpole Island community.

### **Possible next steps:**

#### **1. Dedicate Leadership to Needs Assessment, Planning and Securing Funding**

- Chief and Council with community involvement to initiate HPC and EOL care needs assessment and lead development of longer term Plan based on assessment. Leadership to seek required funding support based on Plan for short and longer term needs. Funding needs likely in a number of areas e.g. for education/training, equipment purchase, facility development, communication, compensation. Consider hiring someone whose job it would be to get some type of nursing facility for elderly and chronically ill.
- Planning process seen as needing to be a partnership with community input. Some of the survey respondents offered to help in this work.
- Consider hiring co-ordinator to help with funding and develop project.

#### **2. Improve Facilities and Equipment**

- Build Retirement/Seniors Home with Palliative beds on WIFN. Home could include graduated housing. Home to provide 24/7 support, access to Spiritual Advisors, Volunteers, trained Counselors and Staff. Care provided by FN people as much as possible. Facility to have a home like atmosphere and be culturally sensitive.
- As per needs assessment, determine what equipment, if available, would contribute the greatest impact in helping to manage care at home e.g. hospital beds, lifts, lifting devices, etc.

### **3. Strengthen Home Support**

- Offer community, family and individual education on HPC and EOLC process/journey, how to manage care, how to access & use available resources and equipment.
- Look at how to provide Seniors with more home support/an advocate to help with basic tasks e.g. taxes, lawns, shopping, etc. Look at merits of a ‘friendly visitor’ type program.
- Examine how funding may be used to increase home support available to seriously ill and their caregivers an offer respite for same.
- Examine current compensation of PSW’s and HSW’s and adjust as necessary.
- Look at possible solutions re transportation. Key challenge in providing support & accessing medical care external to Walpole Island community

### **4. Strengthen Training and Education**

- Look at how training for FN people can be strengthened and in what areas. Longer term goal is providing more care by FN people for FN people in all roles e.g. nurse, PSW, doctor, etc.
- Look for opportunities where ‘hands-on’ experience in HPC and EOLC care can be provided in a training setting e.g. PSW’s/’HSW’s trained for a month in LTC facility on lifts, positioning, mouth care, etc. Pay for training.
- Look at what areas community needs education on e.g. wills, DNR’s, Palliative Care plans and support awareness/education on same.

### **5. Improve Communication & Profile: Internal & External to WIFN Community**

- Strengthen connection with HPC and EOLC resources in broader ESC community and main stream hospital/medical settings to improve understanding of WIFN needs & culture & access to potential education resources.
- Strengthen WIFN communication as part of community education on HPC and EOLC care and valuing of same. Use speakers, local publications, etc. Keep profile of work in this area in the mind of the community.

- Get High School Youth involved with Elders in some kind of EOL program.
- Look at creating a ‘History Page’ in New Seniors Home (or elsewhere) to remember and celebrate the lives of WIFN community members...Consider a ‘digital monument’ to deceased members. Look at how to celebrate ‘birth’ in community as well as recognize death.

## **6. Continue Building Relationship With Spiritual Advisors**

- Encourage ongoing dialogue & involvement in HPC and EOL work of Traditional and Christian leaders to ensure that spiritual beliefs are considered in palliative and end-of-life care and to foster relationships across spiritual advisors.

## **Who to Involve in Planning, Education Development, Implementation & Care/Gap Management?**

Some respondents indicated that they personally would like to be involved in improving palliative and end-of-life care. Respondents identified a broad group of people they thought should be involved in next steps. Key groups including the Chief and Council and representation from people working in Health Care. Several people felt that it was very important that the community be engaged in dialogue with respect to next steps. The comments from respondents noted below speak to the issue of involvement;

“Keep us, the community members informed and make community input available”

“The key people who should be involved ...in this work...are all health programs. They should be working together to provide the best care for our community members. Chief and Council should be involved”

The broad range of people respondents identified as possibly involved in some aspect of this work going forward included;

- Health Care Program providers (Health Centre and Home and Community Care Programs)
- Clients of HCC

- Personal Support Workers and Home Support Workers
- Chief and Council
- Community members
- Elders and youth
- MP's and legislators
- Schools: teachers and students
- Churches
- Traditional Healers
- Christian spiritual people
- People who have the experience of taking care of an elderly parent or chronically ill loved one; family members
- Community Care Access Centre
- Ministry of Long Term Care
- Fairfield and other facilities
- Retired Nurses and Administrators

## **Conclusion**

The Palliative and End-of-Life care survey sampled a small segment of the Walpole Island First Nation community. It was beyond the scope of the project to prioritize support for palliative and end-of-life care over other concerns the Band might have at this point in time. That said the Survey identified clear short and long term issues around palliative and end-of-life care specifically around access to expert medical care and treatment, education, adequate funding and home support. There is strong support for deepening and strengthening the education and training of First Nation's people so that more care can be provided by trained First Nations people. As well, there is strong agreement on the need for a local Retirement or Long-Term Care facility where community members can go when they can no longer live or be supported at home. As one respondent said;

“When people know they are dying, they want to come home”

