



# **Evaluating a Toolkit to Assist Rural Communities in Developing End of Life Care**

**A Master of Public Health Research Project**

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## **INTRODUCTION:**

The need for community-based, client-centred end-of-life care is particularly evident in rural areas in order to allow people to die amongst their family and friends. However, resources are limited and there is often a lack of coordination and communication between the agencies responsible for providing rural community care. In 2008 the North West Community Care Access Centre (CCAC) received funding from the Local Health Integration Network (LHIN) to create a resource, specifically a “toolkit”, that would guide communities in the development of local palliative and end-of- life care programs and facilitate seamless, integrated care. The outcome of this funding was a document called “Building A Community End of Life Care Program: A Toolkit for Action”, which is referred to here as the Toolkit (see Appendix A).

With the Toolkit now being disseminated throughout the region, this project aims to describe how it is being used by certain communities in Northwestern Ontario and how it might be improved to optimize its value for program planning and development. This evaluation is being supported by the Interdisciplinary Capacity Enhancement (ICE) program of research titled “Timely Access and Seamless Transitions in Rural Palliative/End-of-Life Care”. This five year program of research is being funded by the Canadian Institutes of Health Research (CIHR) and involves a team of researchers from across Canada working on ten different projects. Specifically, this evaluation is being supported by ICE Project 9, “Refinement and testing of a conceptual model for developing and delivering rural palliative care programs”, which is being led by Dr. Mary Lou Kelley of Lakehead University and Dr. Allison Williams of McMaster University.

## **LITERATURE REVIEW:**

### **Palliative Care:**

Palliative care (sometimes referred to as end of life care) is a type of health care provided to individuals and families who are living with a terminal or life-threatening illness (Canadian Hospice Palliative Care Association, 1997). The goal of palliative care is to ensure that the person has the best quality of life possible, with an emphasis on comfort, dignity, and pain and symptom management (CHPCA, 1997). Palliative care uses a multidisciplinary approach to address the physical, emotional, spiritual, social, and cultural needs of not only the individual, but their family, caregivers, and community as well (Palliative Care Institute, 1994).

In 2000, the Senate Committee on Social Affairs, Science, and Technology declared that every Canadian has the right to quality end of life care (Senate Committee on Social Affairs, Science and Technology, 2000). In his powerful report on the future of health care in Canada, Roy Romanow states that home care (including palliative care) is “the next essential service” that we must focus on providing to our citizens (2002). He came to this conclusion after extensive consultations revealed that access to these types of services is seen as very important by ordinary Canadians (Romanow, 2002). Unfortunately, it has been estimated that only 15% of Canadians currently have access to appropriate palliative care services (Senate Committee, 2000). Clearly,



one of the great challenges faced by policy makers and health care providers today is to ensure that each and every Canadian is able to access the care that they need, when they need it.

Further complicating the already limited access to palliative care are several factors that may contribute to an even greater demand for such services in the near future. There is a growing trend of individuals preferring to die at home, with estimates that up to 80% of Canadians would prefer to die at home, if given the choice (CHPCA, 2008; Romanow, 2002). The fact that up to 75% of deaths still take place in hospitals or long term care facilities indicates there is a struggle to meet the demand for home-based end of life care services (CHPCA, 2008).

Another factor to consider is Canada's increasingly aging population. The latest Census data revealed that 13% of our citizens are now over the age of 65 (Statistics Canada, 2007). As the baby boomer generation grows older, it is estimated that the number of those over the age of 65 will represent 22.5% of the total population by the year 2026 (Statistics Canada, 2007). As the majority of deaths in Canada are attributed to people over the age of 65, there will be a large number of people in need of end of life care in the near future (Statistics Canada, 2005). This, coupled with the fact that most people wish to die at home, demonstrates a need for greater access to community-based palliative care services.

There is clearly a growing need for programs and services that will allow people to age and die at home and in their communities. It is essential that health care providers, administrators, and policy makers work together now to develop such programs in order to ensure that every Canadian experiences comfort, dignity, and choice at the end of life.

### Rural Health Services:

According to the latest Census data, up to 30% of Canadians live in rural areas (Statistics Canada, 2008). However, rural and remote communities in Canada have long been at a disadvantage when it comes to the provision of health care and related services (Romanow, 2002; Kelley, 2007). Rural communities face many challenges related to the delivery of programs and services that urban communities do not. Some of these challenges include the vast distances between communities; inclement weather (often resulting in poor road conditions); difficulties in the recruitment and retention of health care providers and other professionals; higher rates of chronic diseases including cancer and heart disease; and poorer overall health status (Romanow, 2002; Canadian Cancer Society, 2007). As a result, there is often much more limited access to essential services in rural areas as opposed to in urban centres.

Though rural communities often face great challenges when it comes to delivering health care, there are also several other differences that set them apart from larger, urban centres. Rural towns tend to have a strong volunteer base, more informal linkages and personal relationships between providers and clients (and between the providers themselves), and greater interdisciplinary teamwork amongst health care professionals (Wilson et al., 2006; McKee, Kelley, & Guirguis-Younger, 2007). These can be seen as strengths that can be used to foster better coordination and integration of health care services.

As Romanow found, urban models of health care delivery do not address the unique needs of rural communities (2002). Alternative approaches must be developed that take into consideration the nature of the rural environment (Romanow, 2002). In order to overcome the challenges of being rural, communities need to plan their services and programs differently, building on the strengths that already exist in their communities so as to maximize what limited resources they do have.

### *Rural Palliative Care:*

The lack of services (and limited access to what is available) in rural communities is also evident when it comes to palliative and end of life care (CHPCA, 2008; Kelley, 2007). It appears as though there are many who are unable to remain in their homes during the last stages of life, in part due to the lack of coordinated, comprehensive services. In some cases, rural residents are forced to leave not only their homes, but their communities altogether in order to receive care at the end of life (Romanow, 2002). This is unacceptable, as Romanow makes the case that “a compassionate society must ensure that people have the care and support they need to spend their remaining time at home, if that is their choice” (2002, p.183). It is imperative that we act now to improve access to integrated, coordinated care, because the demand for these services is expected to increase dramatically as the population ages and more people express the preference to die at home.

The need for rural palliative care is great, and it is clear that rural communities should take a different approach than urban communities when developing programs and services. Although there is still limited research on effective models of delivery for rural palliative care services, there have been attempts to conceptualize courses of action that could be taken. For instance, Kelley has created a model that outlines a process that communities may undergo to develop their own palliative care program (see Appendix B; Kelley, 2007). Kelley’s model is based on a theoretical framework of community capacity development. In particular, it incorporates the following community capacity building principles: the focus is on enhancing existing resources and capacities and uses a strengths-based versus a needs-based approach; the process is initiated and undertaken by local providers and solutions are not imposed from the outside; and the process of change is both gradual and ongoing, often happening over a period of years (Kelley, 2007). The model itself is made up of four phases (Antecedent conditions; Catalyst; Creating the team; and Growing the program), with several factors needing to be in place for each phase (Kelley, 2007). Though Kelley’s work is straightforward and easy to understand, some communities may need practical resources to help them translate this conceptual model into concrete action. The Toolkit created by the Emo End of Life Care Committee in conjunction with the North West Community Care Access Centre could serve as such a resource. If successful, this and other planning tools would aid committees in developing their community-specific programs and give them the push needed to move forward and turn their plans into practice.

### **DEVELOPMENT OF THE TOOLKIT:**

The creation of the Toolkit was overseen by Wilma Sletmoen, End of Life Care Coordinator for the North West CCAC. Through her work with communities across Northwestern Ontario she saw the need for a common resource that could be used to help guide end-of-life care program development. With funding from the LHIN in place, the community of Emo was chosen to work on creating the Toolkit at the same time as they worked on developing their end-of-life care program.

The township of Emo is located along the Rainy River, just north of the Minnesota border. It is about a four hour drive west of Thunder Bay (population 109,140), and a thirty minute drive west of Fort Frances (population 8,103) (Statistics Canada, 2006). The population of Emo is 1,305 and the median age of its residents is 39.9, slightly higher than the median age of 39.0 for all of Ontario (Statistics Canada, 2006). Emo's economy is based primarily on the natural resource sector (mining, forestry, and agriculture), though the tourism industry is becoming more important. Emo is currently the main service centre for agriculture in the Rainy River District (<http://www.twspemo.on.ca/>).

The Emo Health Centre consists of 3 acute care beds and 12 long term care beds. The Emo Clinic is located in the basement of the Health Centre and has a stable roster of three full time physician equivalents (<http://www.riversidehealthcare.ca/usemo.html>). Home care is arranged through the North West Community Care Access Centre, and there is an active hospice volunteer program. In 2005 there were a total of nine deaths in Emo; six of these took place in hospital (Habjan, Diamond, & Kelley, 2008). According to their records, the North West CCAC was providing services to 4 palliative clients in Emo in 2007 (Habjan, Diamond, & Kelley, 2008).

Emo was chosen to assist with the creation of the Toolkit because at the time they were in the early stages of their program's development and had a dedicated core group of community members who were willing to meet on a regular basis. The Emo Team was also more than willing to have their experiences documented and to share any resources that they created with other communities. The Toolkit was developed between January and April of 2008 and has since been disseminated to other communities in the region. This makes an evaluation of its use timely.

The Emo Team met bi-weekly during the winter and spring of 2008 to identify the steps that needed to be taken in order to get their program up and running. They then worked together to develop and refine the processes and protocols that needed to be in place prior to putting their program into practice. The Toolkit describes the process of their program's development and provides templates of the various forms and documents created to assist them in its delivery. It is available as a both a hard copy (in a binder) or an electronic copy (via e-mail or on a CD).

The Toolkit has always been viewed as a "living" document which will be continually revised and updated as its various components are put into practice. As such, palliative and end of life care committees are being encouraged to adapt and use the documents contained in the Toolkit however they see fit. Committees can choose to use the Toolkit as a whole, or just take whatever bits and pieces they feel they need to get their own programs started. Each individual form or document can be further revised and cut, copied, and pasted until it is suitable for a committee's

purposes. The intent is to provide a comprehensive resource that can be adapted to reflect the uniqueness of each program and community, so it can be utilized in whatever way is most beneficial to the user.

Because the Toolkit was distributed to other community committees before the Emo Team had the opportunity to put its components into practice, it can be assumed that some vital changes and additions will need to be made to it in order to make it feasible for use during actual program implementation. This, combined with the fact that other committees are being encouraged to make their own adaptations, shows the importance of keeping track of and documenting the changes that are made to the Toolkit, so that everyone can continue to learn from each other as palliative care is organized across the Northwest.

### **PROJECT GOALS:**

This project aims to evaluate how the Toolkit has been used to enhance the planning and implementation of community-based palliative and end of life care programs in two communities in Northwestern Ontario. The overall goal is to determine if the Toolkit would be a useful resource for communities in other rural regions.

The specific project goals are as follows:

- to identify what contents of the Toolkit are most relevant and useful to community-based palliative care committees
- to document how the Toolkit is being used by the committees in Emo and Terrace Bay/Schreiber during their programs' development
- to determine when and how the Toolkit may best be introduced to committees
- to make recommendations for changes or additions to the Toolkit based on committees' experiences using it

### **RESEARCH DESIGN & METHODOLOGY:**

The interpretive paradigm was used to guide the design of this project, and the methodological approach was evaluation research (Denzin and Lincoln, 1998). As indicated previously, the overall aim of the project was to undertake a process evaluation of the Toolkit by using the communities of Emo and Terrace Bay/Schreiber as case studies. This project falls under Dr. Mary Lou Kelley and Dr. Allison William's program of research on "Developing rural palliative care: Evaluating a conceptual model" and has received ethics approval from Lakehead University (see Appendices C & D).

The communities of Terrace Bay and Schreiber are located along the Trans Canada Highway on the north shore of Lake Superior. They are within a 15 minute drive of each other, and share many of the same services. They are located about a 2.5 - 3 hour drive east of Thunder Bay. Terrace Bay is the larger of the two with a population of 1,625, while the population of Schreiber is 901 (Statistics Canada, 2006). The median age for Terrace Bay is 45.6, while the median age for Schreiber is 42.9 (Statistics Canada, 2006). These are much higher than the Ontario average of 39.0, which indicates that both of these communities have an older population. Though

Schreiber has a long history with the railroad, both it and Terrace Bay are now dependent on the forestry sector (<http://www.schreiberterracebay.ca>). Recent shutdowns of the local mills have resulted in massive layoffs, leading many to leave the communities to seek work elsewhere.

The McCausland Hospital in Terrace Bay is a 25 bed facility, with 17 acute care beds and 8 chronic care beds. For the past eight years the community has been trying to raise funds to build a 22 bed long term care wing onto the hospital (<http://www.mccauslandhospital.com>). The North Shore Family Health Team serves both Schreiber and Terrace Bay, with a clinic located in each community. There is currently only the equivalent of 1.5 full-time doctors in the communities, so there is a reliance on short-term rotating locums to provide health care services (<http://www.schreiberterracebay.ca>). Home care is arranged through the North West Community Care Access Centre, and there is also an active hospice volunteer program. In 2005 there were a total of 18 deaths in Terrace Bay, with 17 of these deaths taking place in the hospital (Habjan, Diamond, & Kelley, 2008). The number of deaths in Schreiber was not assessed, though it can be assumed that many of these deaths would have taken place in hospital in Terrace Bay and are captured in the Terrace Bay data. The Terrace Bay/Schreiber End of Life Committee has been meeting since late in 2007. In the fall of 2008 they were presented with a copy of the Toolkit as developed by Emo.

#### *Data collection*

The data collection for this project took place between January and March of 2009 (see Appendix E for project timeline). This researcher made one visit to Terrace Bay/Schreiber to act as a participant observer at their monthly committee meeting. The researcher had also planned to attend a monthly committee meeting in Emo, but that visit had to be cancelled due to poor weather and road conditions. The researcher then conducted key informant interviews with the co-chair of the Emo committee, the chair of the Terrace Bay/Schreiber committee, and one other active member of the Terrace Bay/Schreiber committee (see Appendices F & G for interview guides). A key informant interview was also conducted with Wilma Sletmoen, End-of-Life Care Coordinator for the North West CCAC, who had been responsible for overseeing the regional dissemination of the Toolkit (see Appendix H for interview guide). All of the key informant interviews were conducted over the telephone and were audio recorded. Only one key informant was chosen from Emo because of the researcher's previous experience in working with that particular committee during their development process. In addition, Wilma Sletmoen has been extensively involved with the Emo committee and was able to provide additional details regarding their use of the Toolkit. Finally, other relevant documents that described how the Toolkit was being disseminated and used by the committees were gathered for analysis (see below).

#### *Data sources*

The following data were collected and analyzed during the completion of this project:

- field notes & observations from the Terrace Bay/Schreiber palliative care committee meeting
- information from key informant interviews (4 in total)

- Coordinator Reports that Wilma completes monthly and sends out to each of the 10 palliative care committees in Northwestern Ontario (2 documents total – March Coordinator Report not available at time of data analysis)
- minutes and agendas from Northwestern Ontario palliative care committees from Fall 2008 onwards (4 documents in total)

### *Data analysis*

Once all of the data had been gathered, the researcher used an inductive approach to analysis to ensure that the findings emerged from the data. The analysis process was as follows (see also Appendix I):

#### Level 1 Coding:

First, the researcher listened through the audio recordings of all of the interviews once. She then listened to all of the interviews again, this time typing point form notes that captured each idea expressed by the interviewee. At this point there was no attempt to organize the data, so the result was a long list of point form notes from each interview, without interpretation.

#### Level 2 Coding:

The researcher then read through the interview notes and began to interpret and organize the data based on the initial research questions/goals of the project. Each question was treated as a category for the initial coding. Each piece of data from the interview notes was copied and pasted into a new master document under one or more of the following four categories:

- “How is the Toolkit being used by committees during their program’s development?”
- “What contents of the Toolkit are the most relevant and useful to committees?”
- “How and when should the Toolkit be introduced to committees?”
- “Recommendations for changes and additions to the Toolkit.”

The researcher then reviewed and analyzed the documents that had been collected as data (e.g. field notes & observations, Coordinator Reports), categorizing their contents under the same four categories.

#### Level 3 Coding:

Once all of the data had been organized into the four categories, the researcher reviewed the data and began to seek out recurrent themes that crossed categories. The data was then reorganized into three categories: Use of the Toolkit; Most Relevant and Useful Contents of the Toolkit; and Suggested Changes and Additions to the Toolkit. The data under the category of Use of the Toolkit was then further categorized into the following global themes: “The Toolkit Can Be Used in Several Different Ways”, “There Are Benefits to Using the Toolkit”, and “Committees Face Challenges While Using the Toolkit.” Finally, each of these global themes was conceptualized as a thematic network which helped the researcher identify a number of sub-

themes (Attride-Stirling, 2001). The researcher continued to refer back to the data while creating the thematic networks to ensure that every piece of relevant data was captured in the end results.

## **RESULTS**

The results are organized under the following headings: Use of the Toolkit; Most Relevant and Useful Contents of the Toolkit; and Suggested Changes and Additions to the Toolkit. Each of these sections includes a more detailed description of the relevant themes that emerged from the data analysis.

### **I. Use of the Toolkit**

This section aims to document how the Toolkit is being used by committees to guide their palliative care program's development. It will begin with a brief overview of how the Toolkit has been disseminated so far in Northwestern Ontario, followed by a more in-depth description of its dissemination and use in the community of Terrace Bay/Schreiber. This will be followed by an exploration of themes that emerged while talking to the key informants about their experiences with using the Toolkit.

#### *Regional Dissemination of the Toolkit*

The Toolkit, as developed by Emo, has been available to other community committees since the summer of 2008. Wilma Sletmoen of the NWCCAC has been the "keeper" of the Toolkit and is overseeing its dissemination across Northwestern Ontario. Upon completion of the Toolkit Wilma did not automatically ship off a copy of it to every community; instead, she made an effort to first make committees aware of it via her monthly coordinator report. She let each committee know that the Toolkit was available as a resource and described to them how some of its contents might help them with their work. By fall 2008 Wilma had begun the process of physically introducing the Toolkit to committees. Though she prefers to introduce it in person at a committee meeting by bringing a hard copy with her, she has also sent it to committees electronically when requested or when she is unable to make it to their meeting. Often a committee will photocopy the hard copy to share amongst themselves, and follow up with a request for an electronic copy as well.

Wilma has noted that there is a big difference between a committee having received the Toolkit and having actually done something with it. This has led her to question how much guidance she should give committees about using the Toolkit and what they should be working on first. For now she has just been recommending that the committee members all review it and then discuss it at their next meeting. Interestingly, she has found that the smaller communities have latched onto the Toolkit more readily than the larger ones. Wilma thinks that this may be due to the greater complexity of larger communities which results in them getting bogged down in complicated processes. She also believes that eventually the larger communities will figure out on their own that the Toolkit is of value to them and can be used to assist with their program's development.

Appendix J provides a summary of the Toolkit's dissemination in Northwestern Ontario thus far.

### *Dissemination and Use of the Toolkit in Terrace Bay/Schreiber*

The Terrace Bay/Schreiber End of Life Committee first received a hard copy of the Toolkit in September of 2008. They quickly decided to take turns reading through the Toolkit before their next meeting, so that they could then discuss it as a group. They placed a sticky note in the front of the Toolkit binder with a list of the names of everyone who wanted the chance to read it. They agreed that once a person had looked through it, they would have the responsibility of getting the Toolkit to the next person on the list. Eventually the Toolkit was photocopied and multiple hard copies were being circulated to speed up this process of sharing.

Due to other issues arising, the Toolkit was not fully discussed at a committee meeting until January of 2009. Still not everyone had a chance to look through it, but those who had were asked what they thought would be useful for Terrace Bay/Schreiber. A few people had hard copies of the Toolkit in front of them and read aloud from the parts that they liked. They also used the hard copies to make editing notes on some of the documents that they decided they wanted to adapt. The chair of the committee said that she would get an electronic copy of the Toolkit and change all of the appendices to Terrace Bay/Schreiber terminology instead of Emo. She was then going to e-mail the updated Toolkit out to everyone so that people could use "track changes" to make further revisions. As changes were made they would be sent around to everyone else for additional feedback, and more discussion would be held at subsequent meetings.

As of the writing of this report, the Terrace Bay/Schreiber committee was still in the process of deciding what components of the Toolkit to use, how those components needed to be adapted, and how to go about putting the pieces into practice. However, the committee was planning to continue meeting on a monthly basis for the foreseeable future, and was working on setting up a session with other local health care providers and administrators to present their revised version of the Toolkit and outline their vision for palliative care in their community.

### *Themes*

Several themes emerged from the data that were related to the use of the Toolkit. In the end, three global themes were identified: "the Toolkit can be used in several different ways", "there are benefits to using the Toolkit", and "communities face challenges while using the Toolkit". Each global theme is supported by a number of sub-themes. Thematic networks for each of the global themes are presented in Appendices K, L, and M.

### **Global Theme 1: The Toolkit can be used in several different ways.**

Once the Toolkit is presented to a committee, it is primarily up to them to decide how they want to use it. Though Wilma has offered committees some guidance in this respect, it has become apparent that the Toolkit can be used in several different ways, depending on the community and their stage of program development. The Toolkit may also be used in a number of different ways



within a community as their committee moves from their initial introductory meetings to planning and eventually implementing their program.

### **1. The Toolkit as a Starting Point for Discussion.**

For committees that have just begun meeting, the introduction of the Toolkit can be used as a good starting point for discussion. Because the Toolkit presents a rather developed and detailed program plan, “young” committees have realized that they need to take a step back and first figure out what their role is and what they are working towards before they try to jump in and develop their own program. Reading through documents such as the Path of Care have led committees to take a step back and ask themselves, “what does palliative care look like in our community right now?”, and “what is our vision for palliative care in our community?” The presence of the Toolkit helps them to realize that they need to discuss some of these underlying issues and make sure that they are all on the same page before diving into developing their own program. This can also turn the meeting into more of a sharing session where everyone describes where they fit in and what their agency’s role is in palliative care. Eventually a committee may decide that the best way to proceed is to first determine their goals and objectives and outline what they hope to accomplish as a committee in general before actually using the Toolkit to develop a program for their community.

### **2. The Toolkit as an Example of What Can Be Done.**

The Toolkit can also be seen as an example of what can be done. A lot of committees struggle with trying to figure out what they should be doing, and the Toolkit gives them an idea of what a community similar to theirs (Emo) has already done. While following in Emo’s footsteps can help other committees feel like they are on the right track, the Toolkit also reinforces the notion that there is no right way or wrong way to go about it. The protocols and documents outlined in the Toolkit are just examples of what could be done; it makes it clear that every community is unique and as such will approach things a little differently.

The Toolkit also gives committees a sense of what is possible and shows them that a small, rural community can actually accomplish a great deal by coming together and working towards a singular goal (improving palliative care for their community). In this way the Toolkit can motivate committees to take action while also serving as a form of encouragement, basically giving them the sense that “if Emo can do this, then so can we”.

The Toolkit may also present them with new ways of improving palliative care that they had never thought of before. For example, in Terrace Bay/Schreiber the Toolkit tweaked the idea of case conferencing for some members of the Family Health Team. Up until the introduction of the Toolkit the committee was primarily focused on the community aspects of palliative care (raising awareness of palliative care in the community, educating the public on the resources that are available and how to access them), but once they read through the section on case conferencing they realized that they could also be working on some of the more clinical aspects.

Through Emo's example, it shows committees that they can develop a program, or components of a program, that can enhance what they are already doing in their community. It allows them to see that they don't need to create a whole new delivery model for palliative care and that they just need to enhance and improve what is already being done.

Overall, using the Toolkit as an example of what can be done can give committees a boost of confidence by showing them that they have the ability to accomplish a lot. By documenting the Emo committee's impressive achievement in developing a program for their community, other committees get the sense that they can do the same, even if they don't go about in the same way.

### **3. The Toolkit as the Prototype for a Community's Program.**

Some committees have decided to use the Toolkit as a prototype for their own implementation process. In other words, they plan to create their own Toolkit based on Emo's and use it as their program implementation manual. They view the Toolkit as not only a guide or a resource, but as a key part of the program itself.

For example, the Terrace Bay/Schreiber committee discussed simply changing the documents in the Toolkit to read "Terrace Bay/Schreiber" instead of "Emo", and then adopting it as a whole for use in their community. They would then proceed to "implement" the components of the Toolkit with few changes and see what worked and what didn't. Both the formal (doctors, nurses, physiotherapists) and informal (hospice volunteers) providers of palliative care would be educated on how to use the Toolkit: what forms to fill out, when to fill them out, who to provide copies to, etc. Their version of the Toolkit would then be placed in key locations throughout the community (in the hospital, at the Family Health Team clinic, in the CCAC office) for care providers to refer to as necessary. The Toolkit would essentially be a master copy of all the program forms and protocols that providers might need to access when treating a palliative client. The Toolkit could then be used to orient providers new to the community to the palliative care program. In such cases the new doctor or nurse would be presented with the Toolkit and told to familiarize themselves with it because the Toolkit is their community's program.

### **4. The Toolkit as a Description of the Program Development Process.**

The Toolkit has also been used as a description of the program development process. In particular the narrative portion at the beginning of the Toolkit, which describes in detail how Emo went about creating the Toolkit, has been used by other committees as an outline of the steps they could follow to develop their own program. Because this part of the Toolkit describes the roadblocks and challenges faced by the Emo committee along the way, and how these were addressed and overcome, other committees feel that they can use the Toolkit to learn from Emo's experiences and avoid some of the same pitfalls. In this sense, the Toolkit is seen as a sort of "how to" manual for planning a community-based palliative care program. Rather than focusing solely on the individual forms and documents that are found in its Appendices, committees who use the Toolkit in this way also focus on studying the process that Emo went through to get to where they are. These committees can then devise a process of their own to follow based upon

Emo's, which is helpful when they are trying to decide what they need to do to get started and to get from point A to point B.

### **5. The Toolkit as an Informational Resource Only.**

For some committees, the Toolkit has been viewed as “information only”. These committees tend to have been already working on their program’s development when the Toolkit is first introduced to them, so they do not feel that they need to use it in as direct a way as “younger” committees. In such cases a committee may go through the Toolkit to get an idea of what is in it, but decide to continue heading in their own direction rather than using it to base their entire program on. For example, the Dryden committee had been meeting for a number of years before the Toolkit was introduced to them, and had created their own “to do” list of things that they wanted to work on. Since the Toolkit may contain some forms or documents that would help them to accomplish parts of their “to do” list, they could simply use these components as needed without attempting to adopt the Toolkit as a whole. Other committees have looked through the Toolkit and decided to revisit it after finishing the tasks that they have already started. Though the Toolkit in its entirety may not seem relevant to these committees, they may still go back and use some of its pieces eventually if there is overlap with what they are already doing.

### **Global Theme 2: There are benefits to using the Toolkit.**

While discussing the use of the Toolkit with the key informants it became apparent that committees are finding that there are specific benefits to using the Toolkit to assist with their program development. Identifying and understanding these benefits can aid in the future dissemination of the Toolkit because they can be used to promote its use to other communities, as well as to administrators and managers at the agency level.

#### **1. It generates interest for developing community-based palliative care.**

One major benefit of presenting the Toolkit to a community is that it generates interest in the development of community-based palliative care. In communities where a palliative or end-of-life care committee may already be established, the Toolkit provides them with a purpose for continuing to meet on a regular basis. As discussed previously, committees often start out without any specific goals or objectives in mind, and this lack of direction may lead some members of the committee to question how worthwhile it is to continue to hold regular meetings. The introduction of the Toolkit gives committees a concrete task to start working on together. As a committee goes through the Toolkit and begins to discuss its contents and its applicability to their community, they may gain a sense of momentum and start to actually see that what they’re doing can make a difference and can eventually be put into practice. This in turn can make it easier to recruit other key care providers to join the committee. Rather than being a committee that meets simply out of habit, with little action taking place, the word gets out that the committee is hard at work on the Toolkit, which piques the interest of others and makes them more inclined to join in and actively participate. Once these other care providers hear that the committee is working on some processes and forms that could ultimately impact their work, these people become more willing to participate and contribute to the group’s effort.

Although the Toolkit is generally only introduced to communities that have established committees in place, it has been suggested that it could also be used to generate interest in starting up a palliative care committee in communities where one does not yet exist. For instance, representatives (local nurses) from one such community were given a copy of the Toolkit to look through on their own. As a result these nurses wanted to know more about getting a committee formed in their community, so that they could get people together to “start working” on the Toolkit. Again, the Toolkit provides people with a purpose for meeting, and in this case a purpose for getting a committee up and running.

## **2. It saves time.**

One of the greatest benefits to a committee in using the Toolkit is the fact that it saves them a lot of time during the development of their program. Every key informant spoken to during the course of this study mentioned that the Toolkit has proven to be a major time saver. The fact that committees can just adapt the documents found in the Toolkit rather than having to create their own saves them a tremendous amount of time and effort. Because the work of the committee is voluntary and comes in addition to their regular work as health care professionals, committee members have expressed gratitude for the work that the Emo group put into developing the Toolkit and for sharing it with them. By providing committees with sample forms and other documents, the Toolkit allows them to focus their efforts on actually developing and implementing their program’s processes rather than spending much of their time trying to come up with ways to phrase things properly.

## **3. It is adaptable.**

Another benefit of the Toolkit is its adaptability. As mentioned above, the adaptability of the various forms and documents contained within the Toolkit saves committees time from having to develop their own. Additionally, committees are encouraged to continuously revise these documents as necessary. It is expected that changes will need to be made as components are put into practice, and providing committees with an electronic copy of the Toolkit makes it easy for them to make these updates.

Some of the key informants also expressed an appreciation for the ability to adapt the Toolkit so that it reflects the uniqueness of their community. The Toolkit recognizes that each community has its own individual characteristics that will need to be incorporated into it, and again, committees are encouraged to make whatever changes they feel necessary in order to make the Toolkit work for them. As one key informant expressed, what she likes about the Toolkit is that it allows for a community’s “flavour” to be added to it.

## **4. It uses an inclusive and holistic approach.**

One last benefit to using the Toolkit is its inclusive and holistic approach to palliative care. It ensures that all of the domains of care are considered by including tools for assessing not only a client’s physical or medical needs but their emotional and spiritual needs as well. One key

informant mentioned how care providers may be unsure of how or when to address their clients' non-medical needs, and that the Toolkit offers some good guidance on ways to incorporate these other domains into practice. Though these other domains may often fall through the cracks during program planning and development, the Toolkit ensures that all of the domains are covered.

The Toolkit also focuses on community-based palliative care versus hospital- or long term care-based palliative care. One key informant expressed that she loved the fact that the Toolkit takes a community-based approach, as a lot of people assume that palliative care only takes place in clinical settings. She feels that there will be a greater shift towards community-based palliative care in the future, and that the Toolkit presents a guide for developing this type of inclusive, comprehensive, and collaborative care.

### **Global Theme 3: Committees face challenges while using the Toolkit.**

The last theme that arose out of discussions about committees' use of the Toolkit was the idea that committees are facing a number of common challenges. It is important to identify these challenges in order to make recommendations to improve both the Toolkit itself and how it is suggested that committees use it. It is also helpful for committees to learn that others have faced the same challenges and that they are not alone in their frustrations. By recognizing that these challenges are a part of the process, committees may be more likely to persevere and work their way through them.

#### **1. Defining their committee's role.**

A major challenge that has been experienced by committees is defining their role in not only the program's development but in its implementation as well. There may be questions as to who is ultimately responsible for what, and how much control they actually have in putting a palliative care program into place in their community. Sometimes the processes outlined in the Toolkit can seem overwhelming and it may be difficult for committees to decide where to start.

Due to their lack of direction, a committee may try to jump right into program development without first establishing their overall vision for their community or the short- and long-term objectives that they are working towards. This can lead to committees feeling slightly adrift and asking themselves "well, now what?" after they've gone ahead and revised the Toolkit to reflect their community. Though a committee may use the Toolkit right away to develop documents such as a pamphlet for their community, once that pamphlet is completed they are unsure of what to do next. Without coming up with an overall, long-term plan from the start, committees can lose momentum and have to go back to the drawing board. The introduction of the Toolkit may result in committees "jumping the gun" and diving right into planning a program without first assessing what their community actually needs or what they are hoping to accomplish as a committee.

#### **2. Involving all of the community's palliative care providers.**

Another challenge that committees have faced while using the Toolkit is getting their community's health human resources involved in the process. According to several key informants, having a doctor involved in program development is important because their profession plays such a large role in the delivery of palliative care whether it is community-based or not. Because a doctor in Emo was involved with creating the Toolkit, many of the program components outlined in the Toolkit are physician-driven. However, the lack of doctors in Terrace Bay/Schreiber has meant that there is currently no physician sitting on the committee. This has led the committee to struggle with determining where the doctors should fit into their program; they are unsure of how great of a role to give to physicians in delivering the program without having a local doctor around the table who is able to specify the level of commitment that they and their colleagues are willing and able to make. Ultimately, while Emo's program will heavily involve their physicians, Terrace Bay/Schreiber has realized that they may have to adapt their program to reflect the fact that they simply don't have the same health human resources available to them that Emo does.

It is also important to have representation on the committee from all professions and agencies who are involved in delivering palliative care in order to figure out the logistics of implementing the program once it has been developed. Some committees have grappled with using the Toolkit to plan their program because they have been unable to get certain key individuals or agencies involved and are therefore unsure whether certain components of the Toolkit are applicable to their community or can feasibly be put into practice. This again leaves them struggling to figure out where everyone fits in without having direct input from or knowledge about a particular agency. For example, it is often difficult to get a hospital decision maker to come to committee meetings. Unfortunately, the Toolkit has established that creating communication protocols between the hospital and community is a major priority. When there is no one sitting around the table who can speak for the hospital, committees become stumped as to how to incorporate them into the program and become unsure of how to proceed.

### **3. Getting agency-level commitment.**

Along with ensuring that a representative from every relevant agency sits on the committee comes the challenge of getting agencies to make commitments to both the process and the program that will eventually be ready for implementation. Obviously those who sit on the committee first need their agencies or employers to support their involvement in developing a palliative care program for their community. Once a committee is formed, they depend on further support from their respective agencies in the form of the provision of meeting space and administrative services (e.g. photocopying, preparing meeting Minutes). Some of the activities undertaken by a committee may also require financial resources. For example, once a committee has developed a pamphlet they may need some money to have it printed. Because the committee is made up of representatives from a number of agencies, it is unclear who should be responsible for providing funding. Greater direction from agencies' management regarding what resources they are willing to commit to the palliative care program is necessary in order for committees to move forward with their work. It is essential that committees know that resources will be available to implement the program that they are working so hard on planning.

Agency-level commitment is also needed when it comes time to put the program into practice. Because the development of the program also results in the development of new forms and protocols, agencies must be willing to adapt their current forms and protocols to incorporate the changes that the committee has recommended. Additionally, once agencies approve the use of a new form or protocol, they must commit to educating their staff on its use. Though committee members may be willing to provide the actual education, the agencies must allow time for their staff to participate in such training sessions. Overall, getting this type of agency-level commitment is a necessary but often complicated step and committees could use greater guidance in how to go about it.

#### **4. Dealing with the slowness of the process.**

A major hurdle that several committees have faced while developing their program is the slowness of the process. When the Toolkit is first introduced a committee may feel like all of their work has been done for them and their program will be ready to go within a couple of months, but they soon find that this is not the case. Even when a committee decides to use the Toolkit as the prototype for their program, they find that ongoing, multiple revisions still need to be made. Coupled with the fact that most committee members are doing this work in addition to their regular jobs this means that it can take up to a year or more before a program is ready to be put into practice. This can be discouraging to committees who want to feel that they are making progress in contributing something meaningful to their communities.

The process is also slowed by the fact that there are few opportunities in these small communities to put the various components of the Toolkit into practice. It is impossible to test out a new form or protocol if there is no one currently dying in the community. Often a committee will have to wait some time before a palliative case presents itself that allows them to pilot test their program. A year after creating the Toolkit, Emo is still waiting and does not know for sure if using their Toolkit will actually improve the way that palliative care is delivered in their community.

#### **5. Avoiding duplication.**

A committee may also struggle with wanting to develop their own program based on the Toolkit but also wanting to avoid duplicating services that already exist in their community. In looking through the Toolkit, committees have noticed that there is the potential for a lot of overlap with the CCAC. In particular, the CCAC's newly revised in-home chart contains several components similar to what is also presented in the Toolkit. As a result committees have identified the need to go through both the Toolkit and the in-home chart together to determine how the two can be integrated while avoiding the duplication of certain forms that providers will be asked to fill out.

This also ties in with the challenge of ensuring that all of the key agencies involved in palliative care are represented on a committee. A committee needs to first know what everyone else is doing before they can plan a program that builds on their existing strengths and resources. For example, the Terrace Bay/Schreiber committee decided they want to enhance what is already being done in the community, not create a whole new program. In order to do this, though, they

realized that they needed to first sit down and figure out what exactly it is that is already being done in their community.

## **6. Receiving updates.**

The last challenge that has become evident regarding the use of the Toolkit is determining a way to disseminate updates that are being made to it across the region. Committees have identified that it is helpful not only knowing what people in other parts of Northwestern Ontario are doing, but also seeing examples of some of the forms and other documents that they are developing for their programs. For example, the Terrace Bay/Schreiber and Marathon committees shared their pamphlets and Paths of Care back and forth during different stages of development in order to see if they were on the right track and to provide each other with additional feedback and ideas. Though it would be valuable to have a mechanism in place that allowed committees from across the region to have access to each other's documents, it would take a lot of work and coordination in order to keep up with the updates as they are made.

It has also been questioned whether or not the Toolkit that a committee has received is indeed the "final version" of the Toolkit. Because the Toolkit is seen as a "living" and constantly evolving document, there are changes being made to it on an ongoing basis, even by the Emo committee who created it in the first place. In fact, immediately upon receiving the Toolkit the Terrace Bay/Schreiber committee was curious to know if Emo had put any of its components into practice, and if so, what revisions they found had to be made as a result. It is clear to everyone that certain changes will need to be made as parts of the Toolkit are implemented in the real world, and it is important that all committees are made aware of these changes when they occur, as well as why they have been made.

## **II. Most Relevant & Useful Contents of the Toolkit**

There was a lot of similarity across communities in what they identified as the most useful and relevant components of the Toolkit. For instance, both the sample pamphlet and the Path of Care were identified by several key informants as being the most useful to their committees so far. The pamphlet was regarded as useful because it forces committees to go through the process of finding out what services are already available in their community and how these services can be accessed. In fact, in Terrace Bay/Schreiber the development of their pamphlet led to the identification of a few more people who were involved in palliative care who had not yet been invited to sit on their committee. The pamphlet is also useful in that it provides committees with a concrete activity that they can get to work on right away. Completing their pamphlet provides committees with a quick, easy success and shows them that they can effectively work together as a team. As a result, the committee has a sense of momentum going forward and is eager to move on to the next task.

Working on the Path of Care helps committees determine what the palliative care process currently looks like in their community and identify the linkages that already exist between certain agencies. Once the Path of Care is complete the committee can use it to identify ways to improve how a palliative client flows through the system. This in turn forces them to think about



the actions that they need to take to make their ideal Path of Care a reality, and the committee ends up with a better idea of what they should be working on next.

Other components of the Toolkit that communities found both useful and relevant were the flow chart, the Expected Death in the Home checklist, the case conferencing templates, and the Terms of Reference. The hospital discharge and intake and assessment forms also generated interest from committees and provoked discussion around the need to develop a set of common forms that could flow between multiple agencies. Additionally, the narrative portion at the beginning of the Toolkit was described as useful in that it gave committees insight into what challenges and barriers they could expect to face as they went through the process of developing their program. One key informant stated that the narrative was “a nice read” and a good introduction to the process that they were about to undertake. She also mentioned that it was good to read the description of the struggles that Emo had gone through, because they had gone through some of the same struggles and it was nice to hear that they “weren’t alone in that”.

### **III. Suggested Changes & Additions to the Toolkit**

When asked if any changes could be made to the Toolkit to make it better or easier for committees to use, most of the key informants answered that they couldn’t think of anything. One key informant said that they wouldn’t necessarily change anything because committees just pull what they need from it. Another noted that “what is here is really good and people just need to take what fits for their community and modify it for their community.” Another key informant commented that the Toolkit was easy to use in its present form.

Though all of the key informants were asked if there was anything missing from the Toolkit, they could not identify anything specific. Several key informants commented on the thoroughness of the Toolkit and noted that they haven’t had to access any outside resources because all they’ve needed so far is in the Toolkit. All seemed to agree that as documents are developed by other committees they should be shared or added to the Toolkit.

#### **Suggested Additions:**

Through discussions with key informants and observations of committee meetings, it became clear that although there is nothing explicitly “missing” from the Toolkit there is definitely more that could be added to it in order to make it of even greater use to committees. Appendix N summarizes these suggested additions to the Toolkit, which are discussed in further detail below.

##### **1. Team-building resources.**

The first set of suggested additions have been grouped under the heading “team-building resources” because they have to do with assisting committees in defining their role, their purpose for meeting, and the direction they want to head in. Both the Emo and Terrace Bay/Schreiber committees were planning to work on developing goals and objectives for themselves. Although this should be an activity that committees work on when they first begin to meet together, neither had done so and are just now coming to the realization that it would be beneficial to clarify what

it is that they're actually trying to accomplish. As such, it would probably be of use to include something on goal-setting in the Toolkit. It would be important that committees learn to set both short- and long-term goals, and to ensure that these goals are reviewed on an annual basis.

Along with setting goals and objectives, it was mentioned that it would be useful for committees to also create a work plan before beginning to develop their program. For example, the Terrace Bay/Schreiber committee jumped right into creating their pamphlet and once they were done were left unsure of what to do next. The work plan would summarize what the committee wants to start working on right away, where they want to go next, and what they need to do to get there. This work plan could take the form of a prioritized list of activities or documents they want to work on and a timeline for completing these activities. Essentially, the work plan would operationalize the committee's goals and objectives. It is recommended that a template or example of one committee's work plan be added to the Toolkit.

It has also been noted that some committees would like to organize a strategic planning session for themselves. This type of session would provide a great opportunity for a committee to sit down and discuss their overall vision for their community while also developing their goals and objectives and drafting a work plan. Though it may not be too difficult to find someone from the community to facilitate such an event, it could be useful to have a sample session outline in the Toolkit that can guide the facilitator in conducting the session and provide them with a bit of direction regarding what topics should be covered and what questions could be asked of the committee.

## **2. More guidance around the implementation of a program.**

A much-needed addition to the Toolkit is a section that is focused on the process of implementing a program in a community. Though the narrative portion at the beginning of the Toolkit describes the process that Emo went through to create the Toolkit, this could be expanded to include details on how they have now gone about implementing it. Essentially, committees need to know what they need to do once they have all of their new forms and processes together. For example, the Terrace Bay/Schreiber committee is already asking questions about who will fill out their forms, who will receive copies of the forms, where will the information about palliative clients be stored, and many more. This speaks to the need for a description of the process of putting the components of the Toolkit into practice. This could take the form of a sample timeline that provides details on what a committee had to do and when they had to do it in order to see their program implemented. It could also take the form of a list of possible "next steps" that outlines specific activities that a committee should undertake to facilitate their program's implementation. This list would include activities like spreading the word about the program to other agencies and the community at large and arranging for staff information sessions to educate them on the use of the new forms and protocols.

## **3. Tools to enhance communication.**

It is clear that enhancing communication between different palliative care providers is a major priority for virtually every committee. Though the Toolkit does include some documents that

were designed to improve communication, such as the common intake and assessment form and the hospital discharge form, these were in the early stages of development at the time that the Toolkit was completed and since then Emo has identified other forms and processes that are needed. It has become clear that there may be several forms that need to be developed to get information flowing between hospitals and community providers. For example, there will need to be different ways of tracking when a palliative client simply visits an emergency room without being admitted versus when they are actually admitted or discharged from the hospital. In the case of Emo this gets more complicated because there is no emergency room in their local health centre, so people are sent to the Fort Frances hospital when an ambulance is called. This means that Emo will need to work with both their local hospital and the Fort Frances hospital on communication protocols and information sharing forms.

A question has also been raised regarding the role of the Thunder Bay Regional Health Sciences Centre, where many people from smaller communities are sent for treatment. There is currently no mechanism by which the local palliative care team would be notified when one of their clients is receiving treatment in Thunder Bay, so something needs to be developed that addresses this and then added to the Toolkit.

In addition to improving communication between hospitals and the community team, the Toolkit should also offer some guidelines or examples on how to improve communication between the doctors or Family Health Teams and the CCAC case managers, as well as between First Nations communities and the local palliative care committee. In the case of enhancing communication between doctors and the CCAC, a number of “report back” forms are in various stages of development in several different communities. Once these forms are finalized and approved, they should be added to the Toolkit to provide other committees with examples of what can be done.

When it comes to incorporating First Nations communities into the programs that are being developed, it has been noted that committees may need to further adapt their forms and processes for use with First Nations agencies and providers. Several committees, such as those in Emo and Marathon, have recently started inviting on reserve representatives to join in the process of palliative care development, so as they create these First Nations-specific protocols they can also be added to the Toolkit.

#### **4. More in-depth discussion of consent, client confidentiality, and information sharing.**

One key informant noted that the section in the Toolkit that discusses the issue of consent and client confidentiality could also be expanded upon. In particular, some committees have struggled with figuring out the confidentiality requirements of different agencies and professions. For example, it was stated that although the CCAC may now be using a verbal consent or “circle of care” approach to confidentiality, other professionals or organizations may have a stricter rules around the sharing of a client’s information with other providers. From this perspective it could be helpful to have a brief summary in the Toolkit outlining the confidentiality requirements of agencies that are involved in palliative care across the region, such as the CCAC, the Thunder Bay Regional Health Sciences Centre, and the hospice volunteer program. It may also be beneficial to have a copy of the latest legislation regarding patient consent in the

Toolkit, or at the very least a list of websites where more information could be found on the subject.

It has also been observed that committees may struggle with not only the issue of getting the proper consent from a client but also the details around how a client's information will be used. Committees could use greater guidance on where the information should be stored, how it should be accessed, who should have access to it, and how the information is transmitted between care providers. Again, as committees start putting their programs into practice they could perhaps document their specific protocols and their experiences using them for future inclusion in the Toolkit.

### **5. Resources to guide communities in taking on an advocacy role.**

The last recommendation for an addition to the Toolkit arose out of the researcher's observations and was not directly suggested by any key informant. Though many committees are still in their early stages and thus focused primarily on program development, it can be assumed that once their programs are up and running they may want to broaden their role to one of advocate for community-based palliative care. At least one committee has already expressed interest in wanting to help make palliative care a priority with the Local Health Integration Network, and another has worked on the issue of health human resources that are available in their community. This indicates that it could be useful to have a section on advocacy in the Toolkit. This section could describe the various forms of advocacy and how a committee could get started, while providing examples of advocacy work done by other committees at both the local and regional or provincial levels. Though most committees will be busy with their program planning and implementation for their first few years, having resources on advocacy in the Toolkit could start them thinking about what they want to work towards in the longer term.

## **RECOMMENDATIONS**

Some of the findings of this study can be translated into a set of practical recommendations that can be used to guide the continuing dissemination of the Toolkit. These recommendations, which are described in greater detail below, take into consideration the timing of the introduction of the Toolkit to committees, the format of the Toolkit, the suggested use of the Toolkit, and the ongoing updating of the Toolkit.

### *Timing*

The key informants unanimously agreed that the Toolkit should be introduced to committees right at the beginning. Though one key informant cautioned that the introduction of the Toolkit should not force a committee to proceed in a certain way, she reiterated that the Toolkit can be presented to committees as a guide that will help them determine the direction that they want to take.

Another key informant spoke about how one of the first tasks of a newly formed committee is to find out about what people have done to develop community-based palliative care in other communities. She then said that that is exactly what the Toolkit represents – a guide to what

other people have done that they can learn from and build upon. Introducing the Toolkit in the early stages can save committees a lot of time trying to research on their own what other communities have done and what types of programs are out there.

It is also recommended that the Toolkit could be presented to individuals living in a community where a formal committee has not yet been created. As mentioned before, the Toolkit could then be used by these key individuals to generate interest from other care providers in the community and provide a purpose for getting everyone together for a meeting. A brief overview of the Toolkit at this initial meeting could then provoke discussion amongst the interested parties and as a result the group may decide to continue meeting, eventually forming a committee with the goal of developing their own palliative care program or team.

Overall, the Toolkit can really be introduced at any stage in a committee's development. Though it would be most useful to provide newly formed committees with a copy of the Toolkit, the Toolkit can also be used by veteran committees as an example of what someone else has done. Although these veteran committees may already be quite far along in their program development process, they may still find a form or document in the Toolkit that would be useful for them to adapt.

#### *Format*

Across Northwestern Ontario, committees have received both electronic and hard copies of the Toolkit. It is recommended that committees continue to be provided with the Toolkit in both of these formats. It has been observed that people like to have a hard copy to flip back and forth to during meetings, and that people like to make notes on their hard copies as revisions and modifications are discussed by the committee. Many people also prefer to read through large documents such as the Toolkit on paper rather than on their computer. It should also be noted that multiple hard copies of the Toolkit are needed in each community in order to circulate it to every committee member in a timely manner. Though committees provided with a single copy of the Toolkit could then photocopy it themselves for further distribution, it can speed up the process if they are presented with two or three copies whenever it is first introduced to them.

In terms of the electronic version of the Toolkit, it is recommended that committees be provided with a disc (CD) of the Toolkit at the same time as they are given a hard copy. Though the Toolkit could be e-mailed to committees, it is too large a file to be sent as one attachment and there is the likelihood of certain pieces going missing or accidentally being deleted if the Toolkit is sent in several chunks via multiple e-mails. A CD could be easily tucked into the front of the binder containing the hard copy of the Toolkit so that committees receive both versions at once.

It is important to make sure that an electronic copy always be provided alongside the hard copy because it makes it easy for revisions to be made to the Toolkit if committees decide to adapt some of its components for their own use. In the same vein, it is also recommended that the forms and other documents in the Toolkit's Appendices be made generic rather than Emo-specific. For example, the "Emo End of Life Committee Path of Care" should be retitled

“Sample Path of Care” in future versions of the Toolkit. Again, this would simply make it easier for committees to adapt and put into practice some of the components more quickly.

### *Suggested Use*

It has been found that committees do not require too much guidance on how to use the Toolkit once they have received it. As discussed before, the Toolkit can be used in a variety of ways and a committee should be able to decide for itself how they can best utilize it to assist with their program’s development. Though Wilma initially began suggesting that committees start by looking at the pamphlet and Path of Care, she soon found that she didn’t need to tell them this because committees simply zeroed in on these two documents on their own.

When the Toolkit is first introduced to a committee, it is recommended that it be circulated amongst its members so that everyone can have a chance to read through it on their own before discussing it as a whole. Once the Toolkit has been rotated between all members of the committee, it is recommended that they set aside at least two meetings to discuss it – what they like about it, how they would like to use it, what they think would be the most useful to them, and so on. Because the process of going through the Toolkit and potentially using it to plan a program is so slow to begin with, it is recommended that committees commit to meeting on a regular, frequent (e.g. monthly) basis while they are in the early stages of development.

### *Updating*

The final set of recommendations based on the findings of this study concern the ongoing updates being made to the Toolkit and how to best ensure that these updates are disseminated to committees across the region in an organized and timely fashion. One way to make sure that everyone has access to the most recent version of the Toolkit is to post it in its entirety on the Northwestern Ontario End-of-Life Care Network’s website. Then, as additions and modifications are made they can be posted on the website and everyone will have equal access to them. Eventually the website could be used to house an online repository or library of several different tools and resources that could aid committees in the development of palliative care in their communities.

It is also recommended that as new forms or other documents are developed by specific committees that they are added to the Toolkit or otherwise disseminated to the other committees. The EOL Coordinator should continue to keep tabs on what each committee is working on, and maintain a list of documents that could be added to the Toolkit once completed. Appendix O provides a list of documents that are currently being drafted or used by various committees and that could be added to the Toolkit eventually.

Several key informants also noted that continuing to find out about what other committees are doing would be both interesting and beneficial. In particular, people are wanting to get updates on other committees’ experiences in putting their programs into practice. It is therefore recommended that some planned opportunities for sharing are organized in the near future. One suggestion was to have committee representatives from across the region gather together face-to-

face on an annual basis to do a review of the Toolkit. Everyone would be invited to contribute updates to the Toolkit based on the work that they have undertaken in their communities, and each committee would have the opportunity to share what progress they had made in the last year. If a face-to-face meeting is not feasible, there is the potential to do it via videoconferencing. Another possibility is setting up an online forum or discussion board that lets committees to post messages about their experiences while allowing them to get feedback from other committees so that they can learn from one another as they move forward to program implementation. Clearly, one of the greatest challenges faced by the EOL Coordinator is seeing to it that the Toolkit is being updated on an ongoing basis to reflect what is actually happening in communities across the region, and ensuring that all of the committees have the opportunity to engage with one another to share their experiences and build upon each other's successes.

## **DISCUSSION**

The findings of this project can be linked back to Kelley's conceptual model that articulates the process of developing palliative care in rural communities. It is clear that the data collected during the evaluation of the Toolkit supports the model process as outlined by Kelley. The communities participating in this evaluation found the process of developing their palliative care programs to be slow and ongoing, and found themselves having to backtrack to complete tasks that they felt they should have done earlier, such as developing an overall vision as well as goals and objectives. This finding reflects Kelley's assertion that the process of developing rural palliative care is both gradual and dynamic, with no real end. It also speaks to the fact that it is important for communities to assess and address their antecedent conditions before moving on to the development of their actual program.

Many of the challenges that committees have faced while working with the Toolkit also appear in Kelley's model. For example, the challenge of defining their committee's role supports Kelley's claim that communities need to have a common vision for change before they can proceed to actual program development. The challenge of figuring out where each care provider fits in and how to encourage the participation of these care providers is reflected in phase three of Kelley's model, "creating the team", and specifically in the theme of "getting the right people involved." In phase four of Kelley's model, "growing the program", she discusses the need for communities to have additional resources and management support in order to sustain their programs. This is directly related to the challenge that communities are facing in obtaining agency-level commitment to both their development process and the resulting program. Finally, the challenge of avoiding duplication and enhancing what they're already doing speaks to the community capacity development principle of building on existing resources and taking a strengths-based approach to program development.

Depending on when the Toolkit is introduced, it can be used to move communities through the different phases of the model. If the Toolkit is introduced early on, it has the potential to be the catalyst that prompts the community into action and provides them with momentum to move onto the next phase of the model, "creating the team". The introduction of the Toolkit also forces different community care providers to work together, thus promoting collaborative generalist practice, which is a key antecedent condition in phase one of Kelley's model. If the Toolkit is

presented to relatively established committees it can help them to identify the activities that need to take place during the fourth phase of the model, “growing the program”, such as education, advocacy, building community relationships, and creating external linkages.

Many of the additions to the Toolkit that are recommended as a result of this evaluation are also related to Kelley’s model. In fact, a lot of the things that are “missing” from the Toolkit mirror certain components of the model. For instance, the need for more information on strategic planning and the development of goals and objectives is directly linked to the need for community’s to assess their antecedent conditions in phase one of the model. Another example is the need for more information on advocacy, which Kelley describes as a key component of phase four of the model, “growing the program”. It was also found that there should be more in the Toolkit on improving communication between agencies and community care providers, which is again related to phase four of Kelley’s model where she speaks of the need for communities to work on changing clinical practices by developing new policies and procedures.

Overall, the themes that emerged from this evaluation are directly related to the previous work done by Kelley on the process of developing rural palliative care. It is therefore recommended that the Toolkit be further expanded to incorporate all of the keys to success and conditions necessary for communities to move through the process of developing rural palliative care as outlined by Kelley in her model. If the Toolkit is revised to provide committees with practical resources and planning tools to guide them through each phase of Kelley’s model it will become an even greater asset to communities.

## **CONCLUSION**

Thus far, the Toolkit has received a very positive response from committees that have been presented with it. It has been described as helpful, thorough, and easy to use. Committees appreciate the fact that it can be adapted to reflect their communities’ unique characteristics, which saves them a tremendous amount of time and allows them to focus more on the process of developing their programs. Although different committees may use the Toolkit in different ways, it is clear that it is a good resource no matter how it is used.

Because it has always been viewed as a “living” document, it is understood that the Toolkit will continue to evolve as people use it. A system needs to be developed to keep track of any revisions and additions that are made to the Toolkit, and to ensure that these updates are routinely disseminated to committees across the region. It is important to continue to solicit feedback from committees regarding their experiences in using the Toolkit and suggestions for improvements to it. It would also be valuable to offer committees the opportunity to share their progress with one another and learn from each other’s experiences in planning and implementing a community-based palliative care program.

Though it will always be viewed as a work in progress, the Toolkit in its current form is a great resource for committees to use during the development of integrated, holistic, community-based palliative and end of life care.



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**APPENDIX A**

**BUILDING  
A COMMUNITY END OF LIFE  
CARE PROGRAM:  
A TOOLKIT FOR ACTION**

**AN INNOVATIONS IN COORDINATED CARE  
PROJECT**

**DEVELOPED BY**

**THE EMO COMMUNITY END-OF-LIFE CARE COMMITTEE**

**Funded by the North West Local Health Integration Network**

**In Partnership with the North West Community Care Access Centre**

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### Introduction:

Every Canadian has the right to quality end of life care (Standing Senate Committee, 2000). Our challenge is to ensure that each and every Ontarian is able to access the care that they need, when they need it. The growing trend of individuals preferring to die at home has led to an increased demand for access to community-based palliative services (Canadian Hospice Palliative Care Association, 2007). The fact that 75% of deaths still take place in hospitals or long term care facilities indicates that we have struggled to meet this increased demand (CHPCA, 2007).

It appears as though there are many who are unable to remain in their homes during the last stages of life, in part due to the lack of coordinated, comprehensive services. In particular, people living in rural and remote areas have severely limited access to palliative and end of life care (CHPCA, 2007). Northwestern Ontario is one such area. Though residents here are somewhat accustomed to a lack of services, it has become clear that we need to work harder, and learn how to work differently, to ensure that the needs of our increasingly aging population are met while still making the best use of our limited resources. It is imperative that we act now to improve access to integrated, coordinated care, because the demand for these services is expected to increase dramatically as the population ages and more people express the preference to die at home.

One way to make sure that individuals have choice and dignity at the end of life is to facilitate the growth of locally-developed, community-based programs. These programs build on existing resources in the community, seeking to simply coordinate and integrate what is already available. These programs would be created through interprofessional collaboration at the local level, with the goal of providing a seamless continuum of care to individuals nearing end of life. However, there is little out there to guide communities through the process of creating their own programs. This project hopes to address this gap by providing a tangible resource that is available to communities to access and learn from.

### Project Overview:

In response to the Ministry of Health and Long-Term Care's End-of-Life Care Strategy, the North West Community Care Access Centre (CCAC) has been developing a service delivery model for end of life care in Northwestern Ontario. For the past three years, the CCAC's End-of-Life Care Coordinator has been attempting to establish community-driven programs throughout the region by encouraging local care providers to integrate their existing palliative care services into seamless, client-centred programs.

In late 2007, the North West Local Health Integration Network put out a request for proposals for Innovations in Coordinated Care funding. The CCAC was able to acquire some of this funding to use for integration activities in rural, community-based, client-centred end of life care. This project is the result of that funding.

The primary goal of this project is to facilitate the development of community palliative care programs throughout the region by producing a Toolkit that could be utilized by communities to guide their process. The purpose of this Toolkit is to outline the process undertaken by care providers in one community in order to formalize the delivery of end of life services in their area. The town of Emo, Ontario was chosen as the “pilot site” for this project because it had a committed group of service providers who were already beginning to meet regularly to identify and work on issues needing to be addressed in order to get a community-based program up and running. Emo was also chosen because it is somewhat representative of Northwestern communities, characterized by a small and aging population and distanced from the type of specialized care that is available in urban centres.

It is hoped that documenting the process undertaken by Emo, as well as the challenges they encountered and lessons they learned along the way, will aid other communities in developing their own programs. Also provided in the Appendices of this Toolkit are samples and templates of the forms and documents created by the Emo team to assist them in the delivery of their program. Other communities are encouraged to adapt and use these documents to facilitate the development of their own programs.

## THE PROCESS:

### Introducing the Concept:

The idea to develop a palliative care program in Emo was first brought to the community by Wilma Sletmoen, the End-of-Life Care Coordinator for the CCAC. A key component of the Northwestern Ontario End-of-Life Care Strategy is to assist individual communities in developing their own programs, based on their needs (see Appendix 1). Wilma’s role is to facilitate the development of these programs by working with each community to guide them through the process.

In June of 2007 Wilma created a list of community contacts in Emo who could be interested in being involved with the development of a palliative care program there (see Appendix 2). She then invited these key contacts to a half day community meeting and planning workshop (see Appendices 3 & 4). At this community meeting, Wilma explained the basic concepts of end-of-life care and introduced a model for growing rural palliative care which had been developed by Dr. Mary Lou Kelley of Lakehead University (see Appendices 5 & 6). This model has four sequential phases that frame the process of development and is presented as analogous to a tree, with each program starting out with the roots (Kelley, 2007). Wilma was able to use the model to show the community that the roots, or antecedent conditions, needed to grow a program in Emo were already in place.



The meeting ended with Wilma posing several questions to stimulate general discussion around what a community-based program might look like in Emo (see Appendix 7). These questions also encouraged those in attendance to talk about the current state of palliative care in Emo, what works well and what doesn't, and what needs to be done to move forward. By the end of the meeting, a core group of community representatives decided to start meeting on a regular basis to work together to create an integrated, coordinated palliative care program for Emo.

### Creating the Program:

The newly formed Emo Community Palliative Care Committee managed to meet approximately once a month from August 2007 to January 2008. During these meetings, the core team of providers was identified and a list of issues needing to be addressed was compiled. The Committee also began working on the next steps to move the program forward, which included drafting a program path of care, creating a pamphlet listing palliative-related services available in Emo, and coming up with common forms and communication protocols for the team.

In January 2008, Wilma announced that the CCAC had received Innovations in Coordinated Care funding from the LHIN to hire a part-time facilitator to work with the Emo Committee until the end of March. The Committee agreed to meet every other week while this funding was in place in order to get as much work done as possible and fully take advantage of the time of the facilitator. Hilary Mettam was hired for this role and attended her first Committee meeting in Emo in mid-January.

The first task undertaken by Hilary was to assess the needs and expectations of each individual team member. It was important to determine the level of involvement that each team member saw for themselves and their organizations, along with the type of role that they might assume in the overall development and implementation of the program. It was also important to find out exactly who is collecting what information, the amount of overlap that exists between the information collected by different agencies, and what information may be missing that could be useful when planning a client's care. A list of questions was created to help with the gathering of these responses (see Appendix 8).

The next step was to further define the role of the Committee and determine how the program would operate. It was decided that there would be two main components that made up the program: the Community Team and the Clinical Teams. Essentially, the current Committee would be labelled as the "Community Team", and be responsible for the overall development of the program and providing a forum in which general issues relating to the program could be discussed. The Clinical Teams would be determined on a client by client basis, and would be made up of every provider involved in that particular client's care (see Appendix 9). While the Community Team would be involved in all of the planning, education, and evaluation related to the program, the Clinical Teams would meet on an as needed basis to discuss issues arising from

the care of a specific individual. In order to make the distinction between these two teams clearer, a Terms of Reference was created for each one (see Appendices 10 and 11). A sample agenda was also designed for the Community Team to outline the types of items that might be discussed at their meetings (see Appendix 12).

It was clear from the beginning of the process that developing a Path of Care was of great importance. The Path of Care would outline step-by-step the flow of a client through the program, from the time that they are first identified as having palliative care needs to what would happen after their death (see Appendices 13 and 14). Having a detailed Path of Care that has been created with input from all members of the Committee ensures that every care provider (formal or informal) is aware of what needs to happen, when it needs to happen, and who is responsible for making sure that it happens.

Once the Path of Care was finalized, the Committee was able to identify areas that required further development. Several documents complementary to the Path of Care needed to be created, including: a pamphlet with a brief description of the program that could be given to potential clients; an internal information sheet that could be used to educate frontline care providers about their role in the program; a palliative intake and assessment form to be used to gather information about an individual that could be shared with other team members upon their admission to the program; a special palliative discharge summary to be completed by the hospital, and; a template to guide the process of gathering a Clinical Team together for a case conference.

The Committee decided that two types of pamphlets were needed: one that gave a general overview of palliative care and a description of the Emo program, and one that listed a number of palliative-related services that were available in the community and could be accessed by a client or their caregiver. The pamphlets will be given to potential clients and caregivers by their health professional in order to introduce the program to them. They can also be used to promote the program in the community and to educate the general public about what the program has to offer. The Committee was able to complete their program pamphlet (see Appendix 15) but was still working on the community services pamphlet at the time of writing, so it is not included in this Toolkit. However, the Palliative and Supportive Care Committee of Dryden has created a similar pamphlet listing the services in their community, and it has been included here as a great example (see Appendix 24). There is also the possibility that the information contained in the community services pamphlet will be made available online in the future. The Kenora and Rainy River Districts online database for health and social services, located at <http://kenora.cioc.ca>, is a great tool available for community groups to post information about their programs and services online that can then be accessed by anyone looking for that type of information. As the Committee's work progresses, it could be very beneficial to have an online presence in order to further promote the program, and what it has to offer, to the community at large.

The internal information sheet was created to educate potential members of the Clinical Teams about their roles and responsibilities (see Appendix 16). These potential Team members include, but are not limited to, nurses, homemakers, counsellors, palliative care volunteers, and spiritual advisors. The internal information sheet is our way of letting these frontline care providers know that they are an important and valued member of the Team, and that their insight into the care of a client is greatly appreciated. Along with the Path of Care, the internal information sheet should give these Team members a good overview of exactly what the program is and how they fit into it. In addition, the Committee plans to conduct education sessions with all those providers whose work may be impacted by the program once it is up and running.

A common assessment and referral form was also identified as a key component that had to be developed for the Emo program. This common form is needed to ensure that all agencies involved in the program have access to the same basic information about every client, without each individual Team member having to collect that information for themselves. In the past, each organization had its own intake forms that were filled out, which meant that a client had to repeat their demographic information and medical history over and over again to each of their care providers. With a common form in place, it was felt that one member of the Team, likely the physician or case manager, could gather the necessary information and then forward it on to the other members of the Team. Since both the physicians and the CCAC had similar forms to begin with, it made sense to combine the common elements into one single assessment and referral form that could be used for the Emo program. Though this form is still in its draft stages, it is provided here as an example to show the type of information that is included on it (see Appendix 17). Another possibility that the Team is considering is the use of the Resident Assessment Instrument for Palliative Care (RAI-PC) as a common assessment tool. The RAI-PC was developed by an international team of researchers and is used to measure ten domains including sleep patterns, pain, nausea and breathlessness (see Appendix 29). With Ontario CCACs potentially adopting the RAI-PC for use province-wide, it is definitely worthwhile for communities to consider how it might fit in with their own programs.

The intent behind developing a special hospital palliative discharge form was to be able to provide information about a client's stay in hospital to the rest of the Clinical Team. Individuals who are nearing end of life may be in and out of the hospital several times as their illness progresses, and it is important that the community-based Clinical Team is aware of any changes in a client's condition that occur while they are in hospital. Though the hospital already completes a general form for all patients upon discharge, the Committee thought that more palliative-specific information could be included to ensure that the client's transition from the hospital to their home is better coordinated and that the care provided to them is seamless. As such, a draft palliative discharge form was drawn up in consultation with a hospital representative and is currently working its way through the approval process. The draft version of the form is included here to provide an example of what information might be collected by the

hospital and shared with the rest of the Clinical Team (see Appendix 18). The Palliative and Supportive Care Committee of Dryden has also created a comprehensive palliative admission assessment that is used by their hospital, which is included in this Toolkit as an additional resource (see Appendix 25).

Case conferencing was identified as one of the primary means of communication amongst members of the Clinical Team. A case conference is basically a meeting where all of the client's care providers are gathered together to talk about the physical, social, emotional, psychological, and spiritual needs of that specific client. A case conference can be called at any time by any member of a client's Clinical Team in order to discuss any issues arising from that client's care. It is a forum for information sharing and is designed to improve the integration and coordination of the care of a specific client. For some clients whose care is more complicated, case conferencing may happen on a regular basis; for others, a case conference may never be necessary. It is up to the client's Clinical Team to decide when, where, and how often a case conference takes place. Once a member of the Clinical Team decides that a case conference is needed, they will contact the Emo Clinic, who will then be responsible for getting in touch with the other Team members and setting a time and location for the conference to take place. At the case conference itself, it is likely that either the client's physician or case manager will chair the meeting, but any member of the Team could assume this role. Though it is anticipated that most case conferences will be rather informal in nature, several templates are included in this Toolkit to outline the types of issues that could be discussed at a case conference, and to provide examples of how the proceedings of a case conference might be recorded and disseminated (see Appendix 26). As of the writing of this Toolkit, the Emo Team had just drafted their own case conferencing form, along with guidelines for its use (see Appendices 19 & 20).

Each of the documents described in the preceding paragraphs are key tools that will be used by the Committee to build the best program possible. With each of these components in place and ready to use, the Committee felt prepared to accept the first client into its program.

### Overcoming Roadblocks:

One of the main challenges for the Committee was identifying any potential barriers that could prevent the program from running smoothly once it is implemented. This section describes the three main roadblocks that the Committee encountered during their planning of the program, and how these hurdles were overcome.

#### 1) Defining the program: Palliative versus End-of-Life

The first roadblock that the Committee had to address was deciding how to define the population that would be served by their program. The Committee wanted their program to be aimed at those who are living with an advanced stage illness and nearing end-of-life; essentially, individuals who are expected to die in the relatively near future. The question then arose as to

whether or not the program should be described as providing palliative care or end-of-life care. The term “palliative care” has many possible meanings, and represents different things to different people, so the Committee put together a list of definitions of “palliative” and “end-of-life” (see Appendix 27). This led to a great discussion around which term best described their proposed program. Though the Committee had been calling its work a “palliative care” program since its inception, and was basing it on the Canadian Hospice Palliative Care Association’s model, it was decided after much debate that the name would be changed to “end-of-life care” to better reflect the clientele that would most benefit from the program. It is recommended that other communities take a look at these different definitions and use them to provoke discussion around the goals of their program, who the program will serve, and how they would like to define themselves. Ideally, this discussion would take place sooner rather than later, to ensure that everyone’s expectations are similar and that all Committee members are on the same page when it comes to introducing the program to the community!

## 2) “Plan B” for clients not eligible for CCAC involvement

Another huge challenge that the Committee struggled with was determining how to deal with potential clients who may be ineligible for certain services due to not having OHIP coverage. Basically, the CCAC is only able to provide services for individuals with an Ontario health card number, and in the Rainy River District there are several populations that may not meet this criteria. For example, some Mennonites and on-reserve Aboriginals may not be eligible to receive case management from the CCAC. In addition, any temporary resident, such as an American who might own a camp near Emo, would be unable to access the CCAC and other services. Furthermore, it is quite possible that some individuals may choose not to access CCAC services even though they do in fact qualify for them. Since the CCAC plays a large role in the Path of Care that the Committee developed, and there is a distinct possibility that a situation will arise where the CCAC is unable to be involved, it became clear that a “Plan B” was needed.

The biggest concern with “Plan B” was how to plan for an expected death in the home. In the regular Path of Care, the responsibility for planning an in-home death lies with the CCAC’s case manager. The CCAC already has strict policies and procedures in place that case managers follow when assisting a client to plan their death, and the Committee was unsure of who could best assume this role in cases where the CCAC was unable to. After some investigation into practices in other provinces, it was determined that the client’s physician would be best equipped to assist the client with the planning of death in their home. As such, an Alternate Path of Care was developed to describe what the program would look like without CCAC involvement, and with the physician assuming many of the case manager’s responsibilities (see Appendix 21). In addition, a checklist based on the CCAC’s own procedures was created to guide the physicians in planning an in-home death (see Appendix 22). Unfortunately, until an actual case involving a “Plan B” client arises, we will not know how well the Alternate Path of Care works and whether or not it is truly feasible to reassign the case manager’s responsibilities to the physician. As with

the rest of the program, we have to wait until it is actually implemented to see if there are any areas that need to be reviewed and revised.

### 3) Issues around privacy and consent

The last major roadblock that the Committee had to overcome was how to deal with the sharing of a client's personal health information amongst members of their Clinical Team. In Ontario there are strict regulations around an individual's right to privacy and how information related to their health can be disclosed, so the Committee knew that this could greatly impact the case conferencing component of the program. Upon reviewing the Personal Health Information Protection Act (Ontario Ministry of Health & Long Term Care, 2004), it became clear that the sharing of information amongst designated "health information custodians" was permitted, but that express consent of the client would be needed in order to exchange information with non-health professionals. In the case of Emo's program, those not considered to be health information custodians would include the palliative care volunteers and any spiritual leaders who may be involved in caring for the client. Since these individuals are key providers of care to some clients, and therefore members of their Clinical Team, it was essential that we find a way to allow for the sharing of information with them.

Guided by the PHIPA, a consent form was created for the client to sign (see Appendix 23). The signing of this form indicates that the client (or their substitute decision maker) is giving their express consent for the care providers listed on the form to share information with one another related to the client's condition. The draft consent form was given to the hospital's privacy officer for review, and she in turn sent it to the Office of the Information and Privacy Commissioner for additional feedback. Some suggestions were made to make the form as detailed as possible, to ensure that the client is aware of exactly what types of information might be shared, and exactly who is going to have access to this information (e.g. specifically name each member of the Team on the form). As long as the physician or case manager is able to sit down with the client and explain the purpose and method of the information sharing and have them sign the consent form, it appears that the issue of privacy can be overcome. However, it is recommended that other communities in the midst of developing their own programs contact a privacy officer in their area (e.g. at their local hospital) to guide them through the legal requirements related to issues around consent. As well, the Office of the Information and Privacy Commissioner is a great source of information and can also be contacted directly to provide answers to any questions one might have about this issue (see Appendix 28, List of Online Resources, for their website address).

#### Lessons Learned:

Though the process of developing Emo's program was somewhat accelerated due to the time constraints related to the funding of this project, much was learned during these few short

months that will hopefully prove useful to other communities. One of the most important things to consider when developing a community-based program in a rural setting is how to formalize some of the processes involved while still allowing the program to maintain its flexibility. In Emo, as in many other small, rural communities, palliative care was already being delivered before this project came along, albeit in a somewhat unorganized, informal way. The key to building a successful program is to find out what is already being done, who is doing it, and what needs to happen to structure it in a way so that everybody is kept in the loop. The basic building blocks of the program are already there; the different players involved just need to get together and integrate their separate pieces into one coordinated delivery model. Of course, it must be understood that the Path of Care, case conferencing process and other components of the program are not written in stone and can be adapted as the situation warrants. As mentioned before, it can be expected that the program as it has been outlined in this Toolkit will continue to be tweaked here and there by the Committee as necessary. The program must be seen as continually evolving so that changes can be made along the way to better facilitate how it is implemented.

Another lesson learned was the importance of keeping key stakeholders involved in the planning process. In Emo we found that the core group of Committee members was able to get a lot done by meeting face to face on a regular basis for the duration of this project. Being able to meet face to face allowed us to really hash out the details of the program and identify the processes that needed to be put into place to get it up and running. We only seemed to falter whenever working on a piece that involved an agency that did not have a representative at the Committee meetings. For instance, the hospital was unable to find a representative able to attend all of the Committee meetings, and this proved problematic when it came to developing the palliative discharge summary. However, the hospital did provide the Committee with a contact who was able to work on the discharge summary on their own time; though it would have been beneficial to have this person attend the actual Committee meetings, we were able to consult with them as needed and in turn get things done. Overall, though it would have been nice to have all of the major stakeholders sitting around the table at all of the planning meetings, this is just not realistic. The key is to make sure that you have the buy-in of all of the organizations that will be involved in implementing the program, and at least one primary contact person at each organization who is available to provide feedback on aspects of the program that involve them directly.

One other lesson learned was the value of having some sort of “team-building” event. In our case, the LEAP training session provided by the Centre for Education and Research on Aging and Health (CERAH) fulfilled this need. The two-day LEAP educational event gave all Emo care providers, not just those on the Committee, the chance to come together and talk about palliative care and how it is delivered in their community. The Committee and the clinical community as a whole were re-energized and more determined than ever to get their program up and running. It is recommended that communities who are preparing to launch their own

program incorporate some sort of “kick off” event (ideally with an educational focus) into their plans, wherein all health care professionals and other care providers from the community are given the opportunity to attend and share their experiences, ideas, and expectations.

Overall, the greatest lesson learned is that the potential of small, rural communities to develop their own palliative care programs is huge and relatively untapped. The dedication and hard work of just a few care providers can bring about major changes in the way that palliative care and other services are delivered to the community. Though rural and Northern towns such as Emo are often seen as lacking when it comes to the provision of health care, this couldn't be further from the truth. In fact, the small size and interconnectedness of the community has made it easier to get things done and proven that just a few core people are needed to “take the ball and run with it” on a project such as this. Great programs can be created wherever there is a vision and a willingness to support change, and Emo is proof of this.

#### Next Steps:

Since the program in Emo has yet to accept its first client as of the writing of this Toolkit, we do not know if the processes outlined above will actually work or not! This also means that the proposed program has not undergone any evaluation or assessment. There is a lot to be learned once the program is actually up and running, and as such, one of the most important “next steps” for the Committee will be to determine how and when the program will be reviewed. It is expected that as clients move through the program the process will be continually reassessed, and changes will be made as necessary. It would be beneficial for the Committee to keep track of what changes are made and why, and to eventually share that information with other communities.

The more immediate steps that need to be taken include finalizing some of the key documents discussed previously. Both the common assessment and referral form and the hospital discharge form are still being reviewed by the agencies involved, and approval to go ahead and use these forms still needs to be sought from certain levels of management. It is also possible that several of these forms will need to be further modified to take into consideration the growing use of the RAI-PC as well as the unveiling of the CCAC's revised in-home chart. Clearly, all of the various forms and documents included in this Toolkit are a “work in progress” and will likely continue to evolve as the program grows and develops.

Additional steps that need to be taken involve some professional development and public education. The staff of organizations such as the CCAC, Comcare Health Services, the Emo Clinic, and the hospital need to be made aware of the program and how it may impact their work. The internal information sheet will help with this, but there may also be a need for additional training to be arranged to teach staff and other care providers about such things as the use of the in-home chart, how to conduct a pain assessment, and how to interpret the Palliative



Performance Scale (PPS). Each Committee member will be expected to arrange, and possibly conduct, most of this in-service training for their respective organizations.

The program should also be promoted to the general public. Distributing the pamphlets, setting up information booths at community events, and submitting a press release to the local newsletter are all possible ways to inform the people of Emo that palliative care is available in their community, and also lets them know how to access it. Though all of this may not be necessary in a small town where word of mouth is the best way of getting a message out, it would be nice to have some sort of a program launch that brings recognition to the hard work of the Committee and shows the community that there are such services out there and ready to be used.

Though the process of planning an integrated, comprehensive, community-based palliative care program can be long and arduous, it is hoped that the experiences of the Emo Committee will help you in building your own program. You are invited to use any of the documents included in the Appendices for your own purposes, and encouraged to adapt them as necessary and tailor them to meet the specific needs of your community. With any luck the information shared in this Toolkit will prove useful to you, and we look forward to seeing more palliative and end-of-life care programs emerging from smaller communities throughout Ontario!

## REFERENCES

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# APPENDICES

## **LIST OF APPENDICES**

### **EMO COMMUNITY PROGRAM RESOURCES:**

- Appendix 1: Northwestern Ontario End-of-Life Care Strategy
- Appendix 2: Community Contact List Template
- Appendix 3: Letter of Invitation to Community Meeting
- Appendix 4: Community Meeting Agenda
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- Appendix 7: Questions for Community Discussion
- Appendix 8: Team Member Assessment
- Appendix 9: Organizational Chart for the Program
- Appendix 10: Terms of Reference – Community Team
- Appendix 11: Terms of Reference – Clinical Team
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- Appendix 13: Path of Care – Plan A
- Appendix 14: Flow Chart
- Appendix 15: Program Pamphlet – included as a separate attachment
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Appendix 23: Consent Form

OTHER RESOURCES:

Appendix 24: Community Services Pamphlet - Dryden

Appendix 25: Hospital Palliative Admission Assessment - Dryden

Appendix 26: Sample Case Conferencing templates

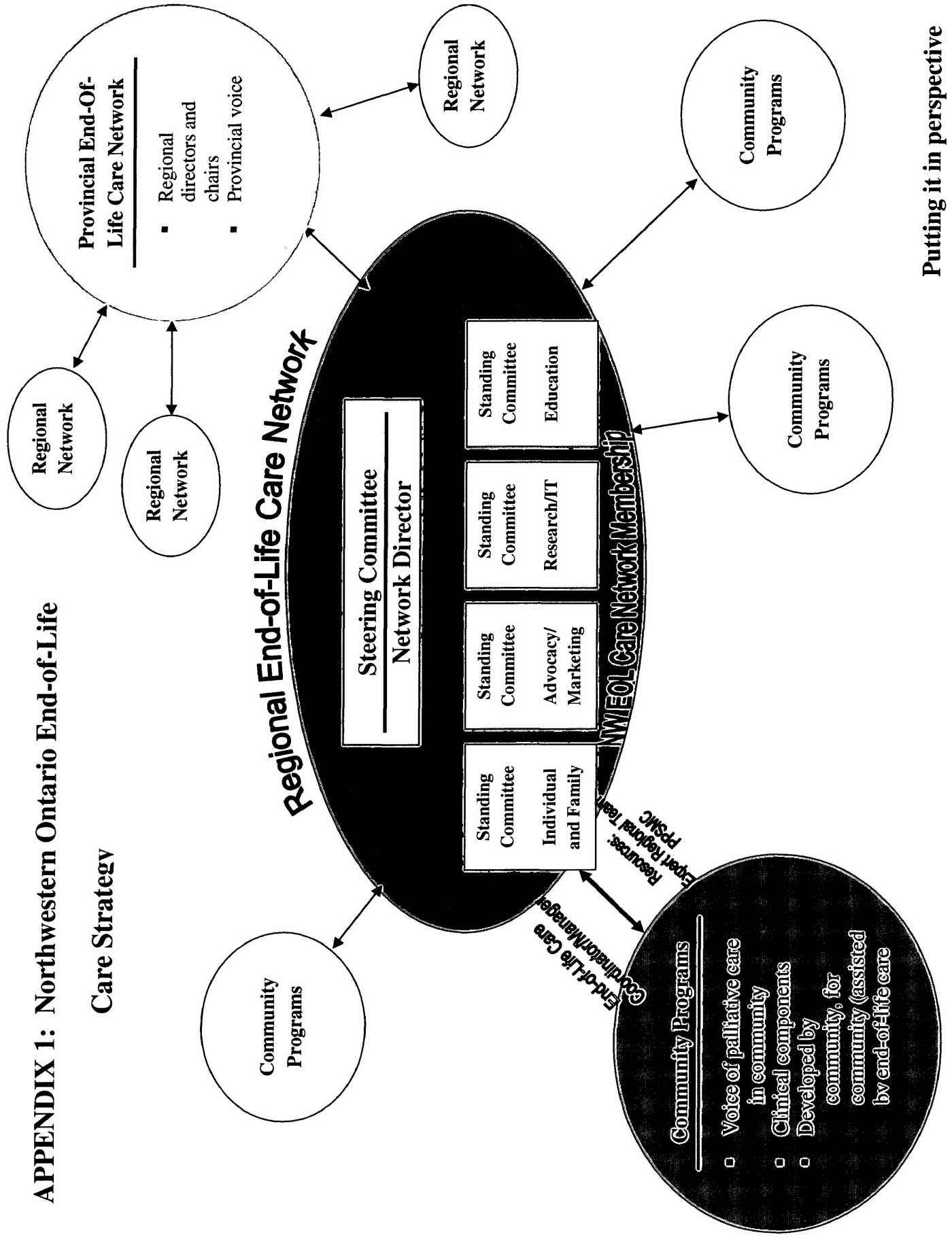
Appendix 27: List of Definitions

Appendix 28: List of Online Resources

Appendix 29: RAI-PC (© inter RAI 2000-2006) – included as a separate attachment

# APPENDIX 1: Northwestern Ontario End-of-Life

## Care Strategy



**APPENDIX 2: Community Palliative / End of Life Care Team – Contact Information**

Agency	Name	Address	Phone/Fax	E-Mail	Communication Preference (Fax? E-mail?)
Ambulance Services					
CCAC					
Comcare Health Services – Nursing					
Comcare Health Services – Homemaking					
Community Support					
Counselling Services					
District Mental Health Services for Older Adults					
First Nations					
Funeral Home					





### **APPENDIX 3: Letter of Invitation to Community Meeting**

**The Northwest Community Care Access Centre invites you to**

**A Palliative Care Community Meeting**

**Tuesday, June 26, 2007**

**2:00 – 5:00 p.m. (snacks provided!)**

**Boardroom (downstairs), Emo Hospital**

**Purpose: A planning workshop, with the goal of developing a community palliative care program for Emo.**

**-- an opportunity for everyone involved in palliative care in Emo to gather and look at how palliative care works here, does it work like we think it should, and, if not, how we can move forward and make it happen.**

**Facilitated By: Wilma Sletmoen, End-of-Life Care Coordinator, Northwest CCAC, Fort Frances.**

**Attached are a meeting agenda and some questions which we will be considering to help focus the discussion. It would be appreciated if you could give some thought to these in advance.**

**If you are unable to attend, please pass this invitation to another appropriate person within your organization. Feel free to share it with anyone else you think would be interested!**

**For more information, please contact Wilma Sletmoen: 807-274-2343 or 1-877-661-6621 [Wilma.sletmoen@nw.ccac-ont.ca](mailto:Wilma.sletmoen@nw.ccac-ont.ca). It would also be appreciated if you could call Wilma before June 22<sup>nd</sup> if you plan to attend.**

## **APPENDIX 4: Community Meeting Agenda**

### **Emo Community Palliative Care Meeting Agenda**

**June 26, 2007 2:00 – 5:00 p.m.**

**Boardroom, Emo Hospital**

**1) Introduction: brief description of concept**

- background
- research model (growing rural palliative care)  
basic concepts (FYI only)  
feedback collected to date in Emo

**2) Review Questions: issues in Community Care**

**3) What could palliative care program look like here?**

- who needs to be involved and how do we involve them?  
possible structure

**4) Next steps: Plan to move forward**

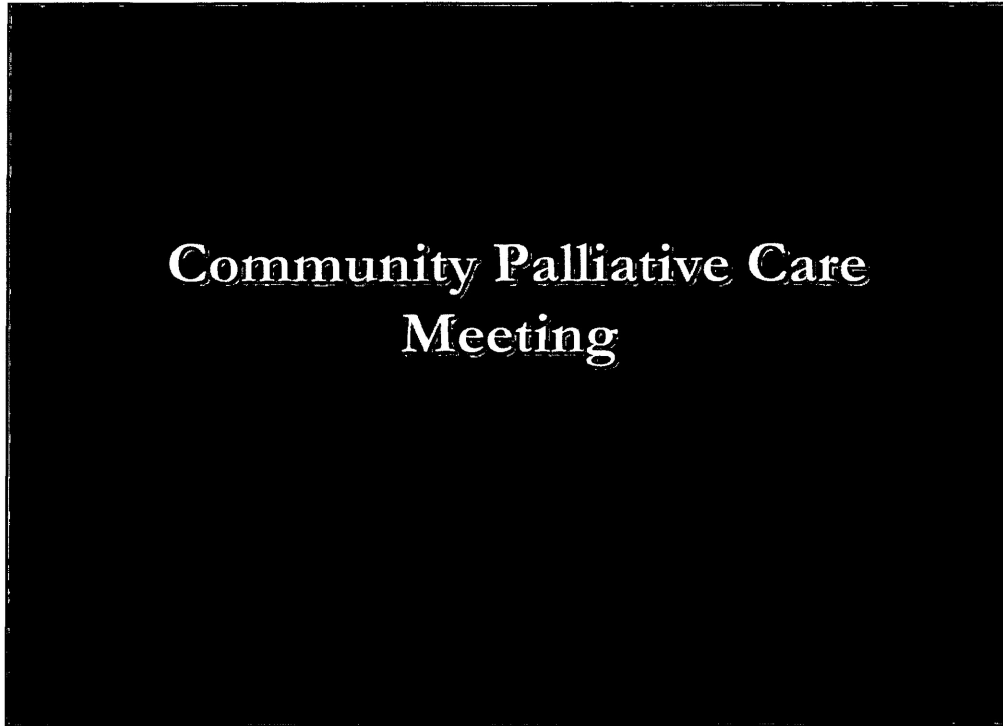
- community voice/contact

**5) LEAP education and PCIP project (will be explained)**

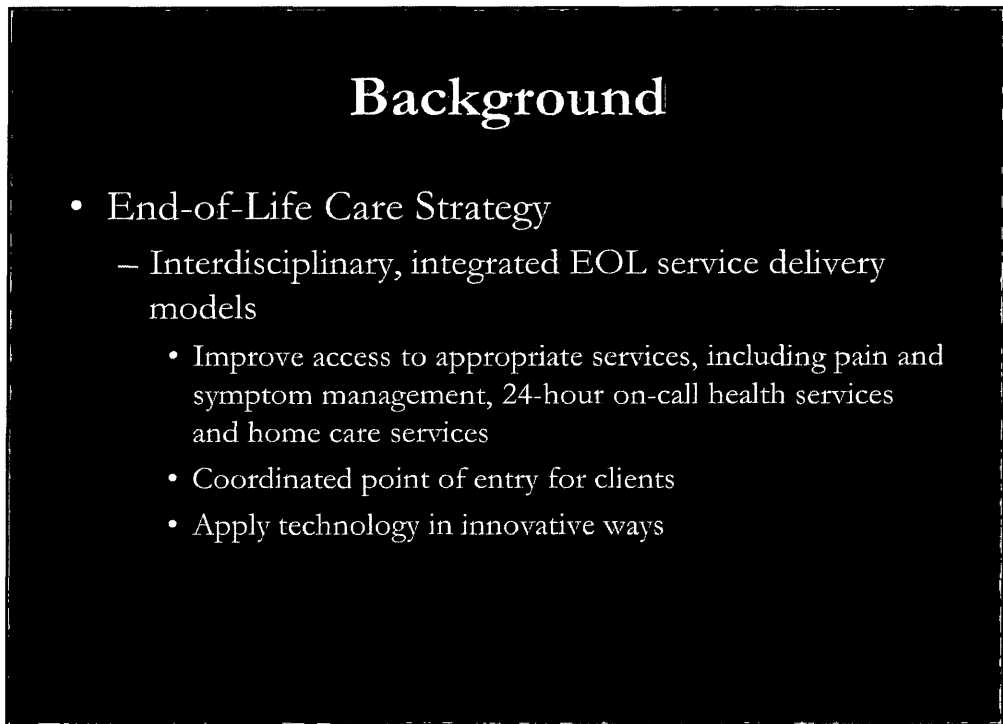
**6) Adjournment – how did it go?**

## APPENDIX 5: Presentation to Community

Slide 1



Slide 2

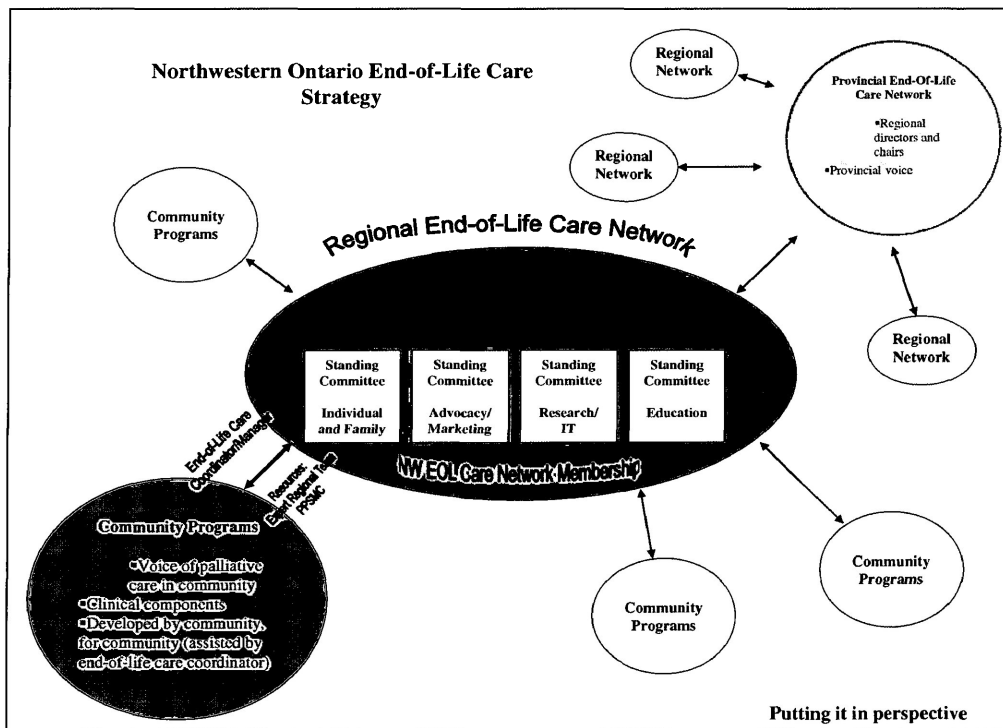


Slide 3

– EOL Care Networks

- Responsible for broad system design
- Coordinate integration of services at system level
- Monitor and assess community needs
- Voluntary collaboration of stakeholders supporting communities in service delivery

Slide 4



## Slide 5

## Basic Concepts

- End of Life Care is based on the CHPCA model and associated definitions and domains of palliative care:
  - Disease management
  - Physical
  - Social
  - Spiritual
  - Practical
  - Psychological
  - End of life/death management
  - Loss and grief

## Slide 6

- Service delivery at community level needs to be developed by the community itself:
  - In a way that works for the community
  - Meets community's particular needs
  - Makes a positive difference to clients, families, and caregivers, both formal and informal

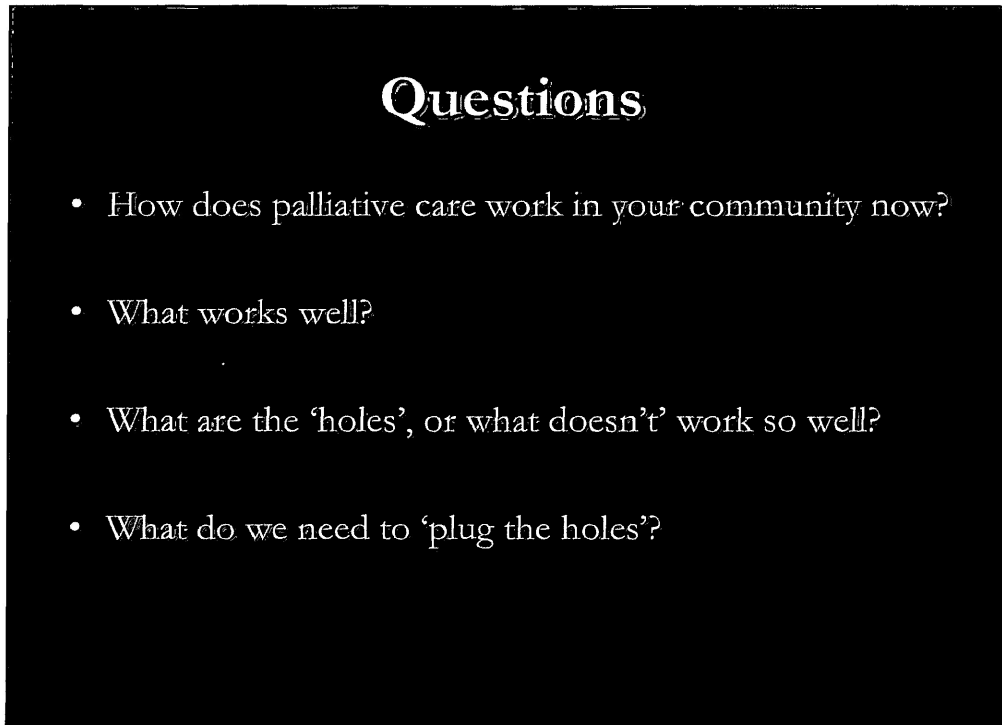
## Slide 7

- Possible components of a model:
  - Team concept
  - Incorporate all settings of care
  - CCAC is the coordinator of community-based care
  - Provides a means of talking to each other—ie: case conferencing, rounds, debriefing
  - Provides a common voice for palliative care in the community and in the network—a contact point
  - Common tools for assessment, referrals, consent; integrated care plans
  - There is ‘no wrong door’ for clients to access care
  - Protocol for expected death in the home
  - Physician involvement is critical

## Slide 8

- End-of-Life/palliative care is happening— it just needs to be more established
- How will we know we’re making a difference— Measuring and evaluating

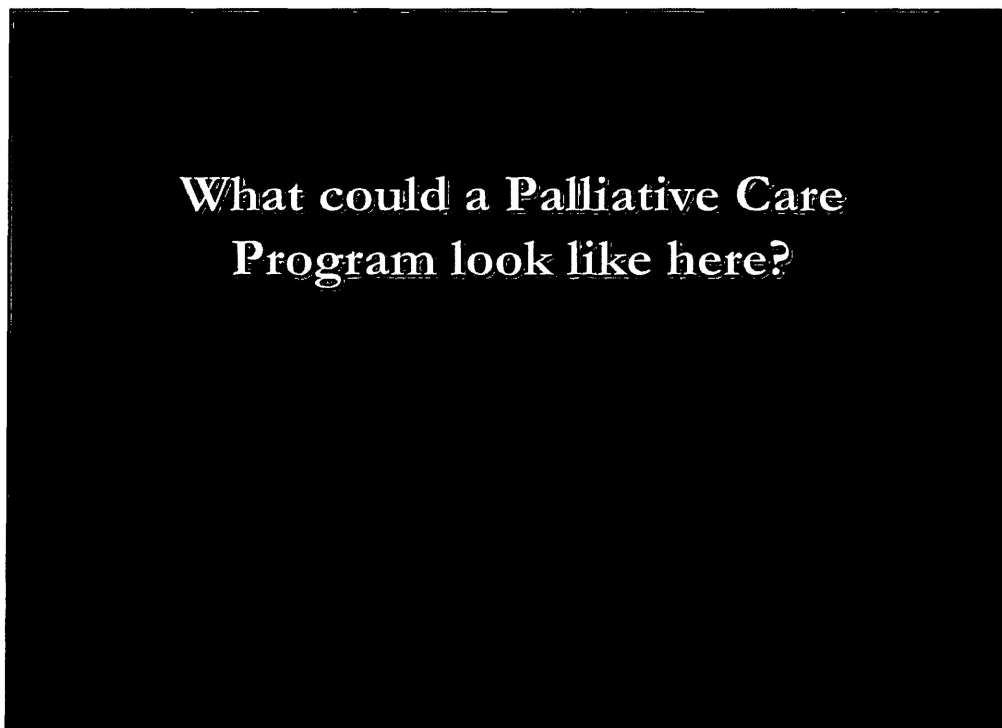
Slide 9

A black rectangular slide with white text. The title 'Questions' is centered at the top in a large, bold, serif font. Below the title is a bulleted list of four questions, also in a serif font.

**Questions**

- How does palliative care work in your community now?
- What works well?
- What are the 'holes', or what doesn't work so well?
- What do we need to 'plug the holes'?

Slide 10

A black rectangular slide with white text. The text is centered and reads 'What could a Palliative Care Program look like here?' in a large, bold, serif font.

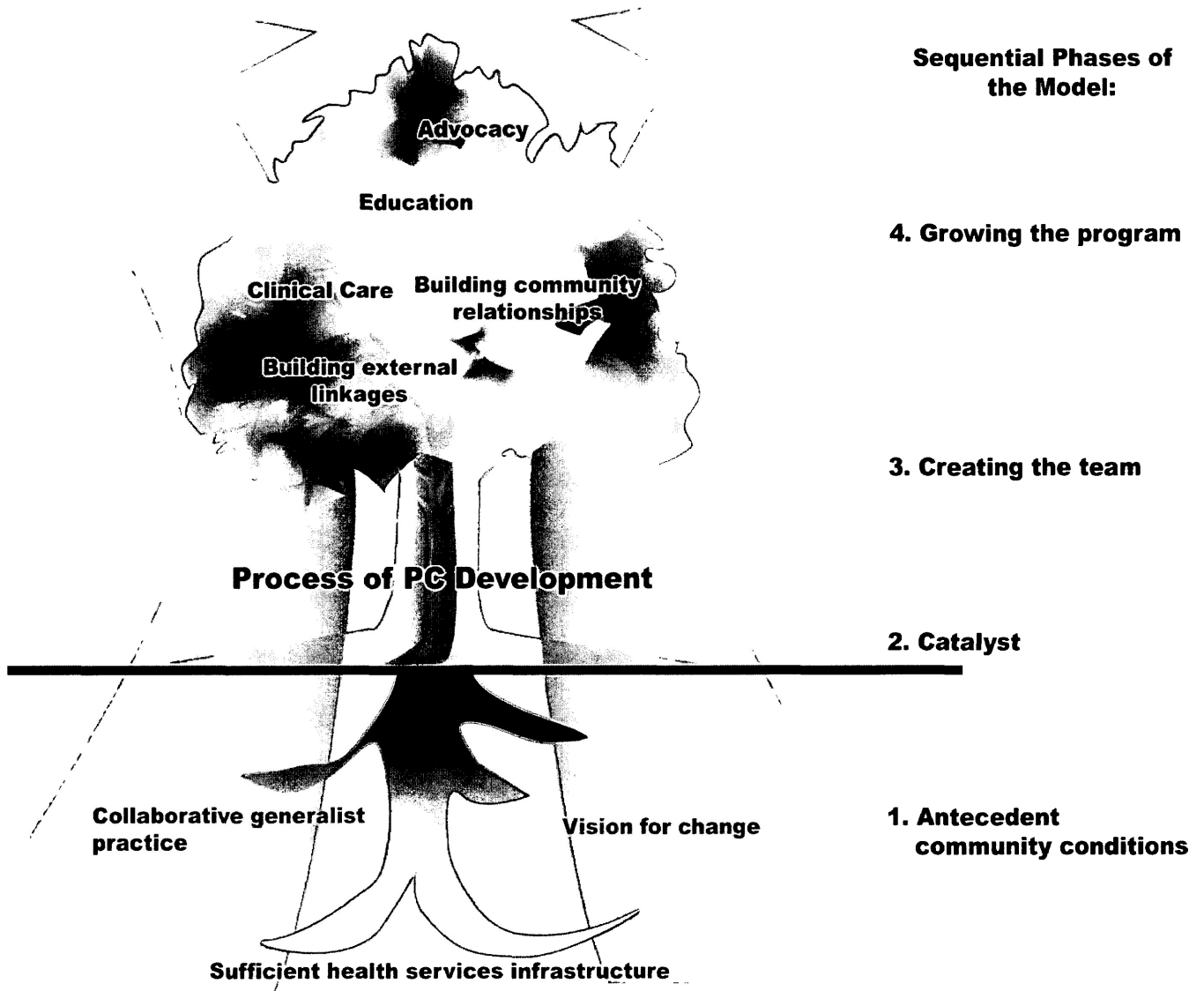
**What could a Palliative Care  
Program look like here?**

Slide 11

**Next Steps: Plan to move forward!**  
**Community voice**



## APPENDIX 6: Developing Rural Palliative Care – A Conceptual Model



## **APPENDIX 7: Questions for Community Discussion**

### **INITIAL COMMUNITY MEETING**

**A. Introduction:** Brief description of concept of community palliative care program, including background, research model being used for community development, basic concepts, and community feedback collected to date is presented by the facilitator.

### **B. Questions for Community Members**

#### **How does Palliative Care work in your community now?**

1.
  - a) What care is available now to people who are dying in your community?
  - b) How is it accessed by patients and families?
  
2.
  - a) Who provides care to people who are dying in your community?
  - b) Where is this care provided?
  
3.
  - a) Is Palliative Care organized in your community? If yes, how does it work?  
How is it being led and managed?
  - b) How did it get started?
  - c) What resources do you currently have?
  
4.
  - a) What are the real strengths in the way that care is now provided to dying people in your community?
  - b) What are the things that you would not want to lose or change in any new program?
  
5. What is the quality of dying in your community now?

6. a) What is your vision in relation to palliative care in your community?  
 b) Do you have any particular goals as a community for palliative care?
7. What are the greatest challenges you have in providing care for people who are dying?  
 (gaps)
8. What do you think needs to happen to address these challenges?
9. Is there anything in your community that will/could prevent you from implementing a palliative care program?
10. How can the EOL Care Coordinator and/or the EOL Care Network assist you?

**C. What could a palliative care program look like here? Who needs to be involved and how do we involve them? Who is your team?**

**Examples of possible structure -**

Palliative care community team--forum for addressing issues/ priorities as identified, community voice for palliative care—public face of palliative care in the community

Clinical team—for case conferencing: community-hospital

Coordinator, joint community/hospital

Interfacility committee—Managerial level, facility decision-makers

**D. Next steps: A Plan to Move Forward**

**Identify priorities; assign tasks. Make arrangements for follow-up.**

## APPENDIX 8: Team Member Assessment

### Developing the Program

#### Questions for individual Palliative Care Team members

##### General background info:

1. Describe your involvement with palliative / end of life care. How do you fit into the picture?
  - What is your role and/or the role of your organization?
  - What services do you offer / provide?
  - How often do you provide services to clients who are palliative?

##### Referral process:

2. How are you made aware of a palliative individual who is need of your services? How do people access your program?
  - Is the client referred to you (e.g. the impetus is on them to contact you), or will another health provider refer you to the client (and you will then initiate contact with the client)?  
What is your ideal referral process? What is the best way for you to be made aware of a situation & get involved? At what stage in the palliative care pathway would you like to become involved?
3. How long does it take to “admit” a client into your service? What is the process (initial contact, intake, phone or face-to-face, home visit, etc)?
  - Are there specific requirements or criteria to be met in order for a client to be able to access your services?
4. What forms do you need to fill out when taking on a new client?
  - What information do you need? How do you get it? How do you keep track of it (forms, notes, electronic/hardcopy)?

What additional info would you like to have access to (other health providers’ schedules, treatment plan, etc)?

What info do you collect that could be shared with other team members (e.g. demographics)?

5. Does your agency have a maximum number of clients that it can serve? Or are you able to accept pretty much anyone at anytime?
6. Do you ever refer your clients to other health services/providers? Who do you refer them to? How do you go about making the referral (informal phone call / e-mail to another provider, make note in in-home chart, just pass along contact info to client)?
7. Once you've taken on a new client, what is the typical chain of events of your involvement with them (from first meeting to death to follow-up)?

#### Role in the Palliative Care Team

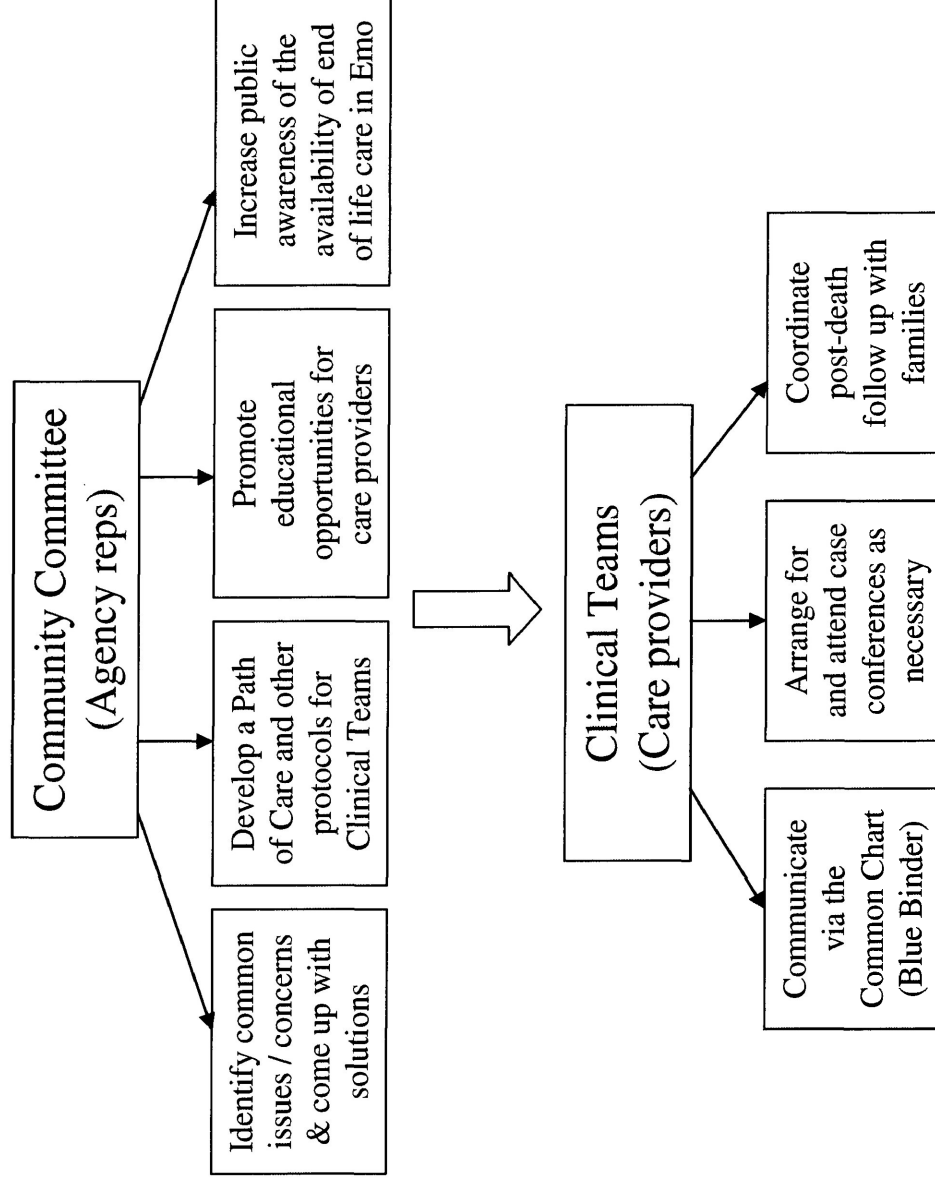
8. Do you see yourself / your agency as part of the "core" team? As a member of the clinical team, or community team, or both?
9. How involved would you like to be:
  - invited to attend family conferences?
  - participate in case conferencing / debriefings?
  - invited to community team mtgs to discuss general issues/concerns?
  - potential time commitment to the Team?
10. What type of communication do you prefer to keep in contact with the Team?
  - E-mail
  - Face-to-face meetings
  - In-home chart notes

#### General Information Needs

11. As you continue to serve the client, what information would you like from other providers (general updates? observations of "risk factors"/behavioural indicators?)?
  - How would you like to receive that info?
  - Who would be the keeper/disseminator of the info?

### APPENDIX 9: Organizational Chart for the Program

#### Emo End of Life Care Program



## **APPENDIX 10: Terms of Reference – Community Team**

### **Terms of Reference Emo End of Life Care Program – Community Team**

#### **Vision**

To provide compassionate, coordinated, and comprehensive end of life care to individuals living in and around the community of Emo.

#### **Terms**

##### Purpose:

The Community Team will help facilitate the coordination of services as follows:

1. Provide a forum for information sharing and promote collaboration amongst Team members.
2. Through information sharing, identify issues and/or deficiencies requiring attention and discussion. Team will then troubleshoot together and come up with solutions that work for everyone.
3. Maintain communication with appropriate networks of care and community partners.
4. Support and share educational opportunities for all involved (professionals' education).
5. Promote the Team as a resource to be accessed by the public / promote awareness of the Team at the local level (public education).
6. Evaluate the program/process on a continuous basis, in order to make adjustments and improve upon the delivery of end of life care in the community.

##### Membership:

Members will include, but are not limited to, representatives from community groups, service providers, and professionals within institutional settings as well as the community. These representatives will have a sincere commitment to individuals, and their families, who are living with advanced stage illness and nearing end of life.

At a minimum, specific areas of representation should include:

Physicians	Mental Health Services
Hospital	Home Care Providers
Community Care Access Centre	Spiritual / Ministerial
Community Counselling	Palliative Care Volunteers

The Chair will be assigned on a rotating basis. The Chair is responsible for: calling meetings, setting the Agenda, and facilitating the meeting itself. Dr. Ingrid Krampetz will serve as the Recorder. If she is unable to attend a meeting, another member will be assigned to act in her place. The Recorder is responsible for taking notes during the meeting and sending them on to Cindy Vergunst (CCAC admin. assistant) in Kenora, who will ensure that the Minutes are distributed to Team members prior to the next meeting.

Meetings:

Meetings will be held a minimum of 3 times a year: in January, May and September/October. At the January meeting the Committee will set the schedule for the rest of the year and also determine who will act as Chair for each meeting.

- Additional meetings may be called throughout the year, according to need.
- Meetings will be scheduled for Wednesday afternoons from 2 - 4 pm.
- Unless otherwise noted, the meetings will take place at the Emo Hospital.

Agendas will be set with input from Team members. The agenda and last meeting's Minutes will be e-mailed/faxed to members at least 24 hours prior to the meeting.



## **APPENDIX 11: Terms of Reference – Clinical Team**

### **Terms of Reference Emo End of Life Care Program – Clinical Team**

#### **Vision**

To deliver compassionate, coordinated, and comprehensive end of life care to individuals living in and around the community of Emo.

#### **Terms**

##### Purpose:

The Clinical Team will help facilitate the coordination of services as follows:

1. Arrange for / participate in case conferencing on an as needed basis.
2. Develop communication tools and processes to facilitate the sharing of information between service providers.
3. Ensure that all providers are “kept in the loop” regarding the client’s (and family’s) needs, concerns, and overall care. Maintain regular and open communication with all other team members.
4. Arrange for debriefing following a death. Use the debriefings to discuss “lessons learned” that might be shared with other Team members.

##### Membership:

The Clinical Team will be comprised of anyone who is directly involved in the care of a particular client who is close to end of life. This could include the client’s case manager, physician, in-home nurses, homemaker, palliative volunteers, spiritual advisor/clergy, counsellor, and mental health service provider. As such, the membership of the Team will vary from client to client.

##### Meetings:

The Clinical Team will meet whenever there is a need to discuss the client’s care with other members of the Team. Any member of the Team may call for a meeting, or case conference, at any time if they have concerns about the client’s care, or if they feel that it would be beneficial to the client.

There will also be a mechanism in place to share information that is discussed at the case conference with members of the Team who are unable to attend. Only those who are directly involved in the care of a client will be privy to such information.

## APPENDIX 12: Sample Agenda – Community Team

Emo End of Life Care Program – Community Team Meeting

Date

2:00 – 4:00 pm

Emo Hospital Boardroom

### AGENDA

1. Call to Order; Regrets
2. Changes, additions to Agenda
3. Review of last meeting's Minutes
4. Business Arising from Minutes
  - a)
  - b)
  - c)
5. New Business
  - a) Issues to be discussed – what's working & what isn't
  - b) General updates from members & their agencies
  - c) Upcoming educational opportunities/training
6. Next Steps/Actions Required
7. For future consideration – no discussion required
  - a)
  - b)
  - c)
8. Next meeting:
9. Adjournment

## APPENDIX 13: Path of Care – Plan A

### Emo Community End of Life Care Program Path of Care - PLAN A

**Principle: Process is always individualized and based upon needs/goals/wishes of the individual and their family and what is assessed to be appropriate for them. It is not based upon comfort level of care providers (we need to support and educate if this is a problem). Plan needs to be flexible and common sense.**

1. Physician – identifies individual who would or could benefit from end of life care; discusses with patient and arranges extended appointment for family conference. Admission to the program does not need to be by physician alone. Any care provider who identifies an individual who could benefit from end of life care can discuss this with the individual and initiate the physician’s appointment.

a. Asks patient permission to include CCAC and, as appropriate, First Nations Home and Community Care Program and Community Health Representative in the family conference\*

– if yes, then MD fills out medical referral form and faxes to CCAC.or First Nations Home and Community Care Program

b. Asks patient/family if there is anyone else whom they want to attend the family conference (e.g. other health care providers, spiritual care).

c. A pamphlet describing the program and related services is given to patient/family to look over prior to the family conference.

\*If the individual is ineligible for CCAC services, or declines the offer to involve the CCAC and/or FN HCC Program, please refer to Plan B – An Alternate Path of Care (*Appendix 21*)

2. Family conference takes place – attended by Physician, CCAC Case Manager, Individual/Family, and whoever else the family wants present.

a. Physician gets Clinic staff to set up an appointment for the family conference. Usually the appointment will be booked for a Monday or a Friday (ideally within a week or two after the patient is identified).

b. Clinic staff will call and verify the appointment with the CCAC Case Manager, individual/family, and anyone else the patient wants invited to the family conference.

c. In general, no “official” paperwork (e.g. intake or assessment forms) will be filled out

during the family conference. The physician and case manager may take some notes, but the goal is to simply answer questions, provide an overview of the next steps to be taken, and introduce the individual/family to the case manager who will be involved in their care.

### 3. CCAC makes timely assessment.

- a. Case manager arranges a home visit with the individual, usually within 1-2 weeks after the family conference has taken place.
- b. The RAI is completed; the concept of the common chart (“blue binder”) is introduced to the client/family but not yet placed in the home. The Common Assessment and Referral Form is filled out.
- c. End of life care checklist kicks in; all domains of care are considered.

### 4. Ongoing care – making sure that the client’s care is comprehensive, seamlessly integrated, and monitored on a regular basis.

- a. Identification of the clinical team
  - Case Manager maintains a list of all service providers (physician, volunteers, nurses, homemakers, counsellor, clergy) who are involved in the care of the client.
  - Case Manager gets the client to sign an “information sharing” consent form; one copy is placed at the front of the in-home common chart, another copy is attached to the client’s clinical chart.
  - Each member of the extended team receives an Information Sheet regarding their role in the End of Life Care Program and how they can contact other team members.
- b. Common chart (a.k.a. in-home chart a.k.a. blue binder)
  - can only be used in homes where there is an identified caregiver.
  - Case Manager must ensure that the individual and the family, and all other care providers coming into the home, are educated on the chart and encouraged to use it.
  - Case Manager will notify Physician when a common chart is placed in the home; Physician will then add a tag to the patient’s electronic health record to indicate that an in-home chart is in place.
- c. Case conferencing
  - a case conference may be called by any member of the clinical team at any time, in order to gather a patient’s providers together to discuss any issues arising from their care.

- a team member who wishes to call for a case conference will contact the Clinic, who will then schedule a time for the conference and notify each member of the clinical team of the arrangements by fax/e-mail. Both the CCAC and the Clinic will keep an up-to-date contact list of members of the clinical team.
- a summary of the issues discussed during the case conference will be written up and distributed to all members of the clinical team, including those unable to attend the meeting.

d. Communication between hospital & community

- the individual/family will be encouraged to bring their common chart with them to doctor's appointments and visits to the hospital.
- if the individual is receiving home care nursing services prior to a hospitalization, the nurse completes left-hand side of admission/discharge form*
- prior to the individual returning home, a Palliative Care Discharge Summary will be completed by hospital staff and a copy will be placed in the patient's common chart.
- a copy of the Discharge Summary will also be forwarded to the patient's Case Manager at the CCAC (tag on patient's electronic health record will remind Physician to do this).

5. Planning for an Expected Death in the Home (EDITH)

- a. Case Manager follows CCAC's EDITH protocol to make the arrangements with the individual/family.
- b. Case Manager's responsibility to make sure all the "ducks are in a row"; Case Manager will notify each member of the clinical team that an in-home death is being planned for.

6. Debriefing following death

- a. Coordinated by the Case Manager - everyone who had a part in the client's care (the clinical team) is invited.
- b. Case Manager makes a bereavement visit to the family/caregiver prior to the debriefing to find out what worked and what didn't. Any important issues identified by the caregiver/family will then be discussed at the debriefing. Case manager also asks the family/caregiver who they would like to have follow up with them again a month later (by telephone call). The person designated to do the follow-up could be any member of the Team that was involved with their loved one's care and that the family feels comfortable speaking to (e.g. palliative volunteer).
- c. Notes will be taken during the debriefing to maintain a record of the issues that were discussed, and any possible solutions and/or program modifications that were suggested.

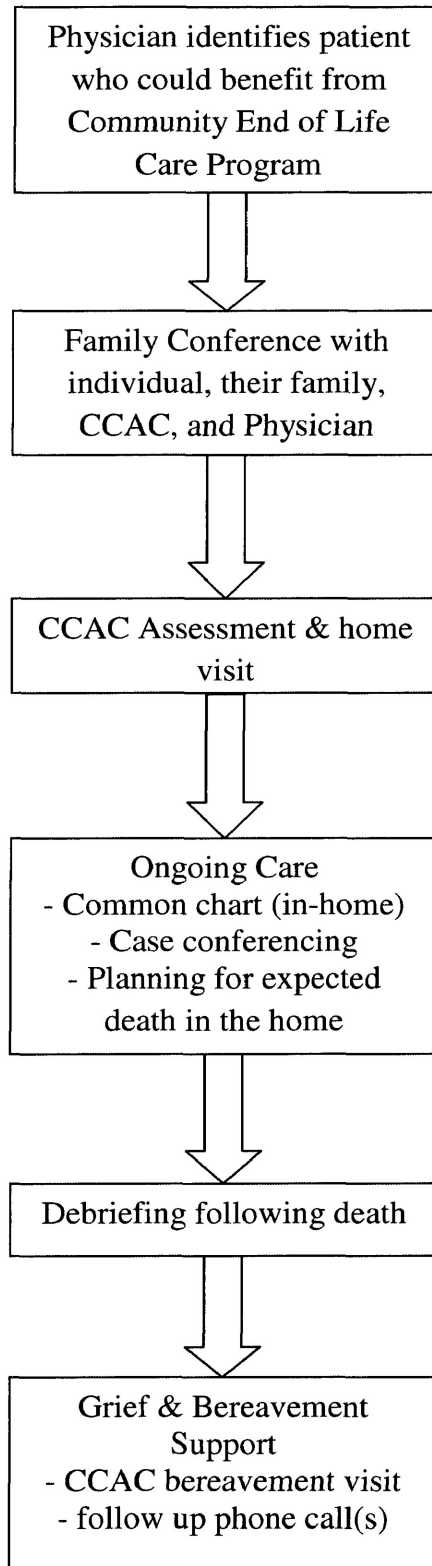
These notes may be later used to identify common challenges/barriers that need to be addressed at the Community Committee level.

## 7. Grief & Bereavement support

- a. The CCAC completes one bereavement visit to the family/caregiver (prior to the debriefing), within 2 weeks following the death of the individual.
- b. A Team member (previously chosen by the family/caregiver) makes a follow-up phone call one month following the death, to check up on the family and see how they're doing. If further support is needed, the Team can provide the family/caregiver with a list of bereavement services offered in the community and/or refer them to Community Counselling. There will also be a variety of grief and bereavement resources (provided by Green's Funeral Home) placed at certain locations in the community that can be accessed by the public.

**APPENDIX 14: Flow Chart**

**Emo Community End of Life Care Program  
Path of Care Flow Chart**



## APPENDIX 16: Internal Team Information Sheet

### Information Sheet for Service Providers (Nurses, Homemakers, Volunteers, etc.) – Orientation to the Emo Community End of Life Care Program

#### *What is the Emo Community End of Life Care Program?*

The goal of the Emo Community End of Life Care Program is to coordinate and integrate the delivery of end of life care in our community. By improving communication amongst all care providers we hope to establish more comprehensive and consistent care for individuals and their families in the program.

The End of Life Care Program has two components:

The Community Committee is made up of representatives from several organizations and is responsible for the overall planning of the program. The Community Committee meets three times a year to discuss general issues related to end of life care delivery in Emo, and will work to come up with common processes and communication protocols to facilitate coordinated care. The Community Committee may also work on issues relating to the ongoing education of service providers, caregivers, and the public at large.

The Clinical Team is made up of everyone involved in the care of an individual who is nearing end of life. The Team may include the individual's physician, case manager, home care nurses, homemakers, palliative volunteers, counsellor, and spiritual advisor. The membership of the Clinical Team will vary from client to client, depending on exactly who is involved in the care of that particular individual.

#### *How do I fit in?*

You are a member of the Clinical Team for each client that you provide palliative-related services to. The **common chart** (aka the blue binder) located in the client's home will be your primary tool for communicating with other Clinical Team members. Though the common chart has been placed in the home by the CCAC, all care providers are encouraged to leave notes in it for other professionals/Team members who visit the home.

As a member of the Clinical Team, you also have the ability to call for a **case conference** with other team members. The purpose of the case conference is to gather the Clinical Team together to discuss issues surrounding the care of a specific client, and to come up with solutions to any problems or concerns that have been identified.

#### *How to call a case conference:*

You should call a case conference if you have any concerns about your client's quality of life or the care that they are receiving. For instance, if you have noticed a drastic change in behaviour, decline in functioning, or have become aware of a change in family/personal circumstances that



may impact their care, it would be beneficial to share your observations with other care providers.

In order to call a case conference you should contact your agency's representative on the Community Committee, or one of the other Community Committee members as listed below. They in turn will contact the Clinic to set up a time/place for the case conference and ensure that every member of that client's Clinical Team is invited.

Community Committee representatives are as follows:

CCAC – *Wendy Derendorf* – 274-6683

Comcare – *Colleen Jolicouer* – 274-3151

Rainy River District Palliative Volunteers – *Jennifer Anderson* – 274-4972

Emo Clinic – *Dr. Ingrid Krampetz* – 482-2323

Community Counselling – *Bernie Gagne*- 482-1442

District Mental Health Services for Older Adults Program – *Jolene Morrissette* – 274-1403

The case conference itself will be somewhat informal and will provide all care providers with the opportunity to share and discuss any important issues related to the care of the client. The overall goal is to provide a forum to increase communication between the carers of a client, so that everyone is aware of the important issues and are on the same page when it comes to addressing any problems.

Since you are a provider who interacts on a regular, face-to-face basis with each client, we want you to feel comfortable requesting a case conference whenever you feel that the individual's care could be improved by having a meeting with all of the patient's care providers. As a key member of the Clinical Team, your input is valuable and welcomed at any time.

If you have any other questions about the Emo Community End of Life Care Program and how you fit in, or if you have any suggestions regarding how the program could be run, please contact a Committee representative, as listed above.

### APPENDIX 17: Common Assessment and Referral Form

## EMO COMMUNITY END OF LIFE CARE PROGRAM COMMON ASSESSMENT AND REFERRAL FORM

HCN	:														Ver:	Expiry:
-----	---	--	--	--	--	--	--	--	--	--	--	--	--	--	------	---------

Surname: \_\_\_\_\_ First Name: \_\_\_\_\_ Int.: \_\_\_\_\_

App. Date: \_\_\_\_\_

Family Physician: \_\_\_\_\_ Attending: \_\_\_\_\_

Address (Street & Mailing):

\_\_\_\_\_

Town: \_\_\_\_\_ Postal Code: \_\_\_\_\_

Phone: \_\_\_\_\_ DOB: \_\_\_\_\_ Sex: (Circle)    M    F

Day / Month / Year

Directions to Home:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Contact: \_\_\_\_\_

Contact: \_\_\_\_\_

Relationship: \_\_\_\_\_

Relationship: \_\_\_\_\_

Telephone: Home - \_\_\_\_\_

Telephone: Home - \_\_\_\_\_

Work/Cell - \_\_\_\_\_

Work/Cell - \_\_\_\_\_

Address: \_\_\_\_\_

Address: \_\_\_\_\_

Spiritual Belief \_\_\_\_\_ Marital Status \_\_\_\_\_

Living Arrangements: (Circle)    Alone    With Spouse    Spouse / Family    Other Non-Related

Other

Language: \_\_\_\_\_

**Risk Codes:**

- A** – Assistive Devices Program    **H** – Home for the Aged    **N** – Nursing Home
- S** – Supportive Housing    **B** – Community Mental Health    **I** – IV Therapy
- P** – Palliative    **U** – Continence Nurse    **C** – Complex
- K** – Consent Shared with ISNC    **Q** – No Ont. HC#/Out of Prov.    **W** – Waiting Placement
- E** – Emergency/Community    **M** – Maternity    **R** – RAI Assessments<sup>4</sup>
- X** – First Nations

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**Primary Dx**

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**Secondary Dx**

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**Date of Assessment:** \_\_\_\_\_

**Referral Source:** (Circle) Community ~ Self ~ Family/Friends ~ Physician ~ Other CCAC

~ In Region Hospital ~ In Region Same Day Surgery ~ In Region Emergency Dept ~ In Region Outpatients ~ In Region LTCF ~ Out of Region Hospital ~ Out of Region Same Day Surgery ~ Out of Region Emergency Dept ~ Out of Region Out Patients

If referral from hospital, please indicate which hospital: \_\_\_\_\_

**Hospital Length of Stay (LOS):** Admit Date: \_\_\_\_\_ Discharge Date: \_\_\_\_\_

**Rx Site:** R/Residence O/Other

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**HISTORY OF PRESENT ILLNESS:**

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**HEALTH HISTORY:**

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**CLIENT UNDERSTANDING OF ILLNESS:**

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**CAREGIVER UNDERSTANDING OF ILLNESS:**

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**CLIENT WISHES WITH ILLNESS:**

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**PRESENT CLIENT STATUS (Including Prognosis, MRSA, VRE):**

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**CLIENT/CASE MANAGER Goals:** (Circle) healing of wound ~ return to self care function ~ return to former functional level ~ teach treatment protocol ~ adjust to altered functional status ~ delay or prevent deterioration ~ assess level of care required ~ support during gradual deterioration

**CURRENT MEDICATIONS:**

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**Medication Management:** Independent YES NO

**ALLERGIES:** \_\_\_\_\_

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**OTHER AGENCIES/GROUP INVOLVEMENT:**

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**SMOKING IN HOME:** YES NO      **PETS:** YES NO

**CURRENT CARE AND CONCERNS:**

**DIET (Type, difficulties, recent weight loss):** \_\_\_\_\_

Elimination: \_\_\_\_\_

Family Issues/Concerns: \_\_\_\_\_

Hearing: \_\_\_\_\_

Mental Status: \_\_\_\_\_

Mobility (Aids, Assist.): \_\_\_\_\_

Equipment Use: \_\_\_\_\_

Pain: \_\_\_\_\_

Respiratory Status: \_\_\_\_\_

Sleep Patterns: \_\_\_\_\_

Special Considerations: \_\_\_\_\_

Vision: \_\_\_\_\_

Socioeconomic (housing, finances, cultural) \_\_\_\_\_

**SERVICES ORDERED**

**DATE DISCUSSED**

**DATE INITIATED**

**COUNSELLING**

\_\_\_\_\_

\_\_\_\_\_

**HOMEMAKING**

\_\_\_\_\_

\_\_\_\_\_

**NURSING**

\_\_\_\_\_

\_\_\_\_\_

**NUTRITION**

\_\_\_\_\_

\_\_\_\_\_

**OCCUPATIONAL THERAPY**

\_\_\_\_\_

\_\_\_\_\_

**PHYSIOTHERAPY**

\_\_\_\_\_

\_\_\_\_\_

**SPEECH THERAPY**

\_\_\_\_\_

\_\_\_\_\_

**SPIRITUAL ADVICE**

\_\_\_\_\_

\_\_\_\_\_

**SOCIAL WORK**

\_\_\_\_\_

\_\_\_\_\_

**VOLUNTEER**

\_\_\_\_\_

\_\_\_\_\_

**SUPPORT SERVICES:** Drugs Pharmacy Dressings Equipment Lab Transportation 02: \_\_\_\_\_

Case Manager Signature: \_\_\_\_\_ Date: \_\_\_\_\_

<b>ROUTING LIST:</b> <input type="checkbox"/> <b>NSG</b> <input type="checkbox"/> <b>PT</b> <input type="checkbox"/> <b>OT</b> <input type="checkbox"/> <b>SW</b> <input type="checkbox"/> <b>SP</b> <input type="checkbox"/> <b>HM</b> <input type="checkbox"/> <b>NUTR</b> <input type="checkbox"/>
<b>CCC</b> <input type="checkbox"/> _____

**APPENDIX 18: Emo Community Palliative Care Program**

**Hospital Admission / Discharge Form**

Name: \_\_\_\_\_

Substitute Decision Maker: \_\_\_\_\_

<p style="text-align: center;"><b>On Admission</b></p> <p style="text-align: center;"><i>(to be completed by community nurse)</i></p>	<p style="text-align: center;"><b>On Discharge</b></p> <p style="text-align: center;"><i>(to be completed by hospital nurse)</i></p>
<p><b>ADMISSION DATE:</b></p> <p><b>PPS:</b></p> <p><b>CODE STATUS:</b></p> <p><b>MEDICATIONS:</b></p>   <p><b>LAST VISIT:</b></p>   <p><b>DIAGNOSIS:</b></p>	<p><b>DISCHARGE DATE:</b></p> <p><b>PPS:</b></p> <p><b>CODE STATUS:</b></p> <p><b>MEDICATIONS:</b></p>   <p><b>TREATMENTS / PROCEDURES DURING HOSPITALIZATION:</b></p>   <p><b>DIAGNOSIS:</b></p>



**PHYSICAL ISSUES:**

**1. Pain**

Location(s) \_\_\_\_\_

Type \_\_\_\_\_

Radiating to \_\_\_\_\_

Severity (0-10) \_\_\_\_\_

Analgesia  
Effectiveness \_\_\_\_\_

Effect on Lifestyle \_\_\_\_\_

**2. Dietary**

Appetite:      good    fair    poor

Swallowing issues \_\_\_\_\_

Chewing issues \_\_\_\_\_

Dentures \_\_\_\_\_

Nausea \_\_\_\_\_

Vomiting \_\_\_\_\_

Dry / sore mouth \_\_\_\_\_

**3. Elimination**

Bladder incontinence \_\_\_\_\_

Nocturia \_\_\_\_\_

Catheter \_\_\_\_\_

                    Last changed: \_\_\_\_\_

Bowel incontinence \_\_\_\_\_

Constipation \_\_\_\_\_

**PHYSICAL ISSUES:**

**1. Pain**

Location(s) \_\_\_\_\_

Type \_\_\_\_\_

Radiating to \_\_\_\_\_

Severity (0-10) \_\_\_\_\_

Analgesia  
Effectiveness \_\_\_\_\_

Effect on Lifestyle \_\_\_\_\_

**2. Dietary**

Appetite:      good    fair    poor

Swallowing issues \_\_\_\_\_

Chewing issues \_\_\_\_\_

Dentures \_\_\_\_\_

Nausea \_\_\_\_\_

Vomiting \_\_\_\_\_

Dry / sore mouth \_\_\_\_\_

**3. Elimination**

Bladder incontinence \_\_\_\_\_

Nocturia \_\_\_\_\_

Catheter \_\_\_\_\_

                    Last changed: \_\_\_\_\_

Bowel incontinence \_\_\_\_\_

Constipation \_\_\_\_\_

Diarrhea \_\_\_\_\_

Ostomy \_\_\_\_\_

Last BM: \_\_\_\_\_

**4. Level of Activity and Mobility**

AAT \_\_\_\_\_

Bedrest \_\_\_\_\_

Aids \_\_\_\_\_

Assist \_\_\_\_\_

**5. Sleeping Patterns**

Describe: \_\_\_\_\_

Insomnia \_\_\_\_\_

Naps \_\_\_\_\_

Nightmares \_\_\_\_\_

**6. Respiratory**

SOB \_\_\_\_\_

Cough \_\_\_\_\_

Inhalation Therapy \_\_\_\_\_

Oxygen \_\_\_\_\_

Chest Sounds \_\_\_\_\_  Sputum \_\_\_\_\_

**7. Sensory**

Hearing Problem \_\_\_\_\_

Hearing Aid \_\_\_\_\_

Vision \_\_\_\_\_

Glasses \_\_\_\_\_

Diarrhea \_\_\_\_\_

Ostomy \_\_\_\_\_

Last BM: \_\_\_\_\_

**4. Level of Activity and Mobility**

AAT \_\_\_\_\_

Bedrest \_\_\_\_\_

Aids \_\_\_\_\_

Assist \_\_\_\_\_

**5. Sleeping Patterns**

Describe: \_\_\_\_\_

Insomnia \_\_\_\_\_

Naps \_\_\_\_\_

Nightmares \_\_\_\_\_

**6. Respiratory**

SOB \_\_\_\_\_

Cough \_\_\_\_\_

Inhalation Therapy \_\_\_\_\_

Oxygen \_\_\_\_\_

Chest Sounds \_\_\_\_\_  Sputum \_\_\_\_\_

**7. Sensory**

Hearing Problem \_\_\_\_\_

Hearing Aid \_\_\_\_\_

Vision \_\_\_\_\_

Glasses \_\_\_\_\_

Taste \_\_\_\_\_

Smell \_\_\_\_\_

**8. Skin Integrity**

skin problem requiring treatment i.e. irritation, burns, surgical wound \_\_\_\_\_

Treatment \_\_\_\_\_

pressure ulcers

Treatment \_\_\_\_\_

**CONCERNS OF CLIENT / FAMILY:**

Management of Disease

Describe:

Social

Describe:

Practical

Describe:

Psychological / Emotional

Describe:

Taste \_\_\_\_\_

Smell \_\_\_\_\_

**8. Skin Integrity**

skin problem requiring treatment i.e. irritation, burns, surgical wound \_\_\_\_\_

Treatment \_\_\_\_\_

pressure ulcers

Treatment \_\_\_\_\_

**CONCERNS OF CLIENT / FAMILY:**

Management of Disease

Describe:

Social

Describe:

Practical

Describe:

Psychological / Emotional

Describe:

Spiritual

Describe:

End-of-Life Planning

Describe:

Loss / Grief

Describe:

**FAMILY ISSUES / CHALLENGES**

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**OTHER PERTIINENT INFORMATION**

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Spiritual

Describe:

End-of-Life Planning

Describe:

Loss / Grief

Describe:

**FAMILY ISSUES / CHALLENGES**

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**OTHER PERTINENT INFORMATION**

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**NEXT DR'S APPT.** \_\_\_\_\_

APPENDIX 19 – Case Conference Form

**CASE CONFERENCE FORM**

Clients Name: \_\_\_\_\_ Date & Time: \_\_\_\_\_

Meeting Place: \_\_\_\_\_

ATTENDANCE:

- |          |          |
|----------|----------|
| 1. _____ | 5. _____ |
| 2. _____ | 6. _____ |
| 3. _____ | 7. _____ |
| 4. _____ | 8. _____ |

If client/family not in attendance, are they aware of conference?    Y    N

**REASON CASE CONFERENCE CALLED:**

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**DISCUSSION & COMMENTS:**

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<b>MULTIDISCIPLINARY ISSUE</b>  <b>(reasons for meeting)</b>	<b>PLAN OF ACTION</b>  <b>(desired outcome)</b>	<b>TEAM MEMBER RESPONSIBLE</b>	<b>REPORTED OUTCOMES</b>  <b>(follow up)</b>

CLIENT/FAMILY INFORMED OF OUTCOME? Y N

## APPENDIX 20 - Case Conference Guidelines

### Guide to Case Conference

1. Deal with initial concerns
2. Other issues in relation to domains of care:

Disease Management—any changes

Physical Symptoms:

- a) Pain
- b) Nausea/Vomiting
- c) Continence
- d) Infection
- e) Insomnia
- f) Respiratory
- g) EOL symptoms

Psychological

- a) Emotions
- b) Fears

Social

- a) Changes/distress
- b) Family --emergency explained  
--after hour support  
--bereavement risk

--respite options

Spiritual

- a) Religious
- b) Alternative

Practical

- a) Activities of daily living
  - equipment
  - home modifications
  - mobility
  - hygiene
- b) Financial

EOL Care

- a) Planning—carers/bereavement
  - allowances
  - ownership issues
  - advance directives
  - expected death in the home protocol
  - wills/funeral

Loss/Grief

- a) counselling
- b) bereavement



## **APPENDIX 21: Alternate Path of Care (Plan B)**

### **Emo Community End of Life Care Program Alternate Path of Care – PLAN B**

**--for use when individual is ineligible for CCAC or FNHCCP services, or declines the offer to involve the CCAC or FNHCCP**

1. Family conference – Physician, Individual/Family, and whoever else the family wants present.
  - a. Physician advises individual about various services they could benefit from (counselling, mental health, volunteers, spiritual) and how to access them.
- 2.. Ongoing care – all domains, tools and processes at our disposal as appropriate
  - a. Identification of the clinical team
    - Physician maintains a list of all service providers (physician, volunteers, nurses, privately paid home care nurses, counsellor, clergy) who are involved in the care of the client.
    - Physician gets the client to sign an “information sharing” consent form; one copy is given to the client, another copy is attached to the client’s clinical chart.
    - Each member of the extended team receives an Information Sheet regarding their role in the Palliative Care Program and how they can contact other team members.
  - b. Case conferencing
    - a case conference may be called by any member of the clinical team at any time, in order to gather a patient’s providers together to discuss any issues arising from their care.
    - a team member who wishes to call for a case conference will contact the Clinic, who will then schedule a time for the conference and notify each member of the clinical team of the arrangements by fax/e-mail. The Clinic will keep an up-to-date contact list of members of the clinical team.
    - a summary of the issues discussed during the case conference will be written up and distributed to all members of the clinical team, including those unable to attend the meeting.
3. Planning for an Expected Death in the Home (EDITH)

- a. Physician completes the Expected Home Death Checklist to make the arrangements with the individual/family.
- b. Physician's responsibility to make sure all the "ducks are in a row"; the Clinic will notify each member of the clinical team that an in-home death is being planned for.

#### 4. Debriefing following death

- a. Coordinated by the Physician/Clinic - everyone who had a part in the client's care (the clinical team) is invited.
- b. Notes will be taken during the debriefing to maintain a record of the issues that were discussed, and any possible solutions and/or program modifications that were suggested. These notes may be later used to identify common challenges/barriers that need to be addressed at the Community Committee level.

#### 6. Grief & Bereavement support

- a. A Team member (previously chosen by the family/caregiver) makes a follow-up phone call one month following the death, to check up on the family and see how they're doing. If further support is needed, the Team can provide the family/caregiver with a list of bereavement services offered in the community and/or refer them to Community Counselling. There will also be a variety of grief and bereavement resources (provided by Green's Funeral Home) placed at certain locations in the community that can be accessed by the public.

**APPENDIX 22: Expected Death in the Home Checklist for Physicians**

**EXPECTED HOME DEATH CHECKLIST  
for Physicians**

**PART 1 – Is the patient able to die at home?**

- Patient has expressed wish to die at home \_\_\_\_\_
- Client can be safely and comfortably supported at home based on clinical status  
\_\_\_\_\_
- Family/Informal Caregiver support – available and committed \_\_\_\_\_
- More than one informal support person \_\_\_\_\_
- Alternate Physician has been designated to act in my absence \_\_\_\_\_
- Myself and my Alternate are available to conduct home visits \_\_\_\_\_
- Nursing provider: \_\_\_\_\_  
Available 24/7?      Y     N

**PART 2 – What you need to ask about & document in the care plan**

- Any private pay services that the patient uses \_\_\_\_\_
- Any other organizations that are involved with the client (Palliative Volunteers, District Mental Health for Older Adults) \_\_\_\_\_
- Spiritual Advisor \_\_\_\_\_
- Specific customs prior to death \_\_\_\_\_
- Specific customs post death \_\_\_\_\_

Special equipment needs \_\_\_\_\_

**PART 3 – What you need to set up / make sure is in place**

Roster of informal caregiver support \_\_\_\_\_

Confirm Substitute Decision Maker \_\_\_\_\_

Advance Directives known \_\_\_\_\_

Personal Support Worker available 24/7 \_\_\_\_\_

Back up plan (what will happen if unable to die at home?) \_\_\_\_\_

In-home charting in place \_\_\_\_\_

DNAR placed in the home \_\_\_\_\_

Expected Home Death Notification Form sent to police (where applicable) \_\_\_\_\_

Family educated on crisis management – who to contact (medical, emotional, psychological, spiritual) \_\_\_\_\_

Family aware of who to call at time of death \_\_\_\_\_

Family aware of who to call if death occurs unexpectedly \_\_\_\_\_

Pronouncement – nurse or physician \_\_\_\_\_

Certifying the death – physician or Nurse Practitioner \_\_\_\_\_

Funeral Home notified and agreeable to remove body \_\_\_\_\_

Clinical Team aware of plan – copies of care plan sent to other providers involved in patient’s care \_\_\_\_\_

**APPENDIX 23: Consent Form**

**CONSENT**

My health professional has explained the purpose of the End of Life Care Program and I give permission to discuss my medical history and diagnosis and to disseminate information (which could include general observations made by care providers and information about social support & services provided), to the following providers who may be involved with my care:

*Physician(s):* \_\_\_\_\_

*CCAC Case Manager:* \_\_\_\_\_

*Dietician:* \_\_\_\_\_

*Community Care Nurse:* \_\_\_\_\_

*Homemaker / Home Care Worker:* \_\_\_\_\_

*OT / PT / Speech Pathologist:* \_\_\_\_\_

*Counsellor:* \_\_\_\_\_

*Spiritual Leader / Pastoral Care:* \_\_\_\_\_

*Palliative Volunteer Coordinator:* \_\_\_\_\_

*Community Mental Health Service Provider:* \_\_\_\_\_

*Other Care Provider, as condition warrants (please specify):* \_\_\_\_\_

I have notified my health professional of any medical or other information I want withheld.

\_\_\_\_\_  
Name

\_\_\_\_\_  
Health Professional securing consent

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Signature of Health Professional

\_\_\_\_\_  
Date

\_\_\_\_\_  
Date

## **APPENDIX 26: Sample Case Conferencing Templates**

- **End of Life Care Case Conference Form (4 pages)**  
Adapted from: Department of Health and Community Services. Northern Territory Government, Australia. [http://www.nt.gov.au/health/comm\\_health/palliative/guidelines\\_forms.shtml](http://www.nt.gov.au/health/comm_health/palliative/guidelines_forms.shtml)
- **Case Conference Guide (1 page)**  
Adapted from: Australian General Practice Network - Rural Palliative Care Resource Kit. <http://www.adgp.com.au/site/index.cfm?display=24281&filter=i&leca=75&did=65829096>
- **Clinical Team Meeting Outlines (1 page each)**

**Case Conference Form End of Life Care**

Date of Case Conference \_\_\_/\_\_\_/\_\_\_

Patient Name ..... D.O.B. ....

Patient consent obtained and documented      Yes                       No                       N/A

Substitute decision maker consent obtained and documented      Yes                       No                       N/A

Patient/SDM present at case conference      Yes                       No

Patient/SDM informed of outcome of conference      Yes                       No                       N/A

Health care Providers:

Name	Participation Code	Discipline	Organisation	Phone	Fax	Copy sent

Participation codes:    P: present at meeting      T: telephone      V: video conference      NP: not present





### Management Table

Problem	Codes	Patient goals of care and Management goals	Management Steps	Person/People responsible	Expected outcomes	Review date
1.						
2.						
3.						
4.						
5.						
6.						
7.						

**Problem Codes**

- 0. Pain control
- 1. Other symptom control (e.g. dyspnea, oedema)
- 2. Functional issue (e.g. difficulty walking, assistance with showering, assistance with taking medications)
- 3. Psychological distress (e.g. depression, anger, guilt)
- 4. Social issue (e.g. carer coping, carer availability, increasing dependence, change in relationships)
- 5. Spiritual concern (e.g. religious issues, "Why am I here?", "What does it all mean?")

**Follow up Plan**

Review by each individual Health Care Provider

Yes  When \_\_\_\_\_ As needed  No

Repeat Case Conference

Yes  When \_\_\_\_\_ As needed  No

Care Plan to be developed

Yes  When \_\_\_\_\_ As needed  No

**Plan for Documentation**

Case Conference form prepared

Yes  No

Case Conference form distributed

Yes  No

GP summary to be prepared by GP (optional)

Yes  No

Signature of GP responsible for case conference.....

GP Name and Address:

.....  
.....  
.....  
.....

## Case Conference Guide

<b>SYMPTOMS</b>	<b>NOTES:</b>
Pain Nausea/Vomiting Continence Infection Insomnia/Fatigue Respiratory EOL Symptoms	
<b>ADL'S</b> Equipment Home Modifications Mobility Hygiene	
<b>FAMILY</b> After Hour Support Respite options Bereavement Risk Emergency Explained	
<b>PLANNING</b> Carers/Bereavement Allowance/s Ownership Issues Advanced Directives Expected Home Death Wills/Funeral	
<b>PSYCHOSOCIAL/ SPIRITUAL</b> Counselling Religious Alternative Bereavement	



### CLINICAL TEAM MEETING

**PATIENT INFO:**

NAME:	
GP:	
DIAGNOSIS:	
DATE OF BIRTH:	
DATE OF MEETING:	

**LIST OF ATTENDEES:**

NAME	ROLE

ISSUES TO BE DISCUSSED	CURRENT SITUATION	PLAN / ACTION REQUIRED
<b>ADLs</b> – provide info. on current capacity for activities of daily living, any aids or equipment required & home modifications.		
<b>Symptoms</b> – list current symptoms being experienced.		
<b>Psycho/social</b> – outline family and social supports & any complexities. Also list any services providing respite support.		
<b>Health management plan</b> – outline the plan for treatment of symptoms & list the providers of this care.		
<b>Advance care planning</b> – list the patient’s wishes for future care options or determine if this is known.		
<b>Death planning</b> – outline the patient & family’s wishes. If it is a home death, determine if the family is aware of what to do.		

## APPENDIX 27: List of Definitions

### DEFINITIONS

#### **Palliative Care:**

##### Canadian Hospice Palliative Care Association:

Palliative care is a special kind of health care for individuals and families who are living with a life-threatening illness that is usually at an advanced stage. The goal of palliative care is comfort and dignity for the person living with the illness as well as the best quality of life for both this person and his or her family.

Retrieved March 6, 2008, from [http://www.chpca.net/menu\\_items/faqs.htm#faq\\_what](http://www.chpca.net/menu_items/faqs.htm#faq_what)s

##### World Health Organization:

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patients illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Retrieved March 6, 2008, from <http://www.who.int/cancer/palliative/definition/en/>

##### Centre for Education and Research on Aging & Health (Lakehead University):

Palliative Care is the active compassionate care of persons who are chronically and terminally ill, primarily directed towards improving the quality of life at a time when the goal is not cure. The emphasis of palliative care is on the control of pain and symptoms, and on meeting physical, emotional, spiritual, social and cultural needs. It is multidisciplinary in its approach,

encompassing the person, family, caregivers, and the community in its scope, and extends to include grief and bereavement.

Retrieved March 6, 2008, from <http://gerontology.lakeheadu.ca/?display=page&pageid=4>

### Southwest End of Life Care Network (London, ON):

In Canada, the terms palliative care, hospice care and supportive care are often used interchangeably. Palliative care provides comfort, support and care to individuals and families who are living with or dying from, a progressive life-threatening illness, or who are bereaved. Palliative care aims to meet the physical, emotional, psychological and spiritual needs of the person and the family.

Retrieved March 6, 2008, from <http://www.thehealthline.ca/PalliativeCare/index.aspx?id=33>

## **End of Life Care:**

### Oxford Handbook of Palliative Care (UK):

End of life care is an important part of palliative care, and usually refers to the care of a person during the last part of their life, from the point at which it has become clear that the person is in a progressive state of decline.

End of life care is usually a longer period than the time during which someone is considered to be "dying". In the UK it is mainly health care professionals who use the term end of life care, whereas patients and their families are more likely to refer to terminal illness and terminal care. The time at the end of life is different for each person, and each person has unique needs for information, for support and for care.

Retrieved March 6, 2008, from <http://www.avert.org/palliative-care.htm>

### Southwest End of Life Care Network (London, ON):

End-of-life care strives to provide physical, emotional and spiritual care and support to individuals, their caregivers and families during the final stages of life.

Retrieved March 6, 2008, from <http://www.thehealthline.ca/PalliativeCare/index.aspx?id=1>

### B.C. Ministry of Health:

End-of-life care is supportive and compassionate care provided during the remaining days, weeks or months of a client's life. It is provided wherever the client is living -- in their home, in hospital, a hospice, residential care facility or an assisted living residence. Palliative care services relieve, eliminate and/or control symptoms so those facing death, and their loved ones, can devote their energies to embracing the time they have together.

Retrieved March 6, 2008, from <http://www.healthservices.gov.bc.ca/hcc/endoflife.html>

Adapted from the Center to Advance Palliative Care (USA):

	<b>Palliative Care</b>	<b>End-of-Life Care</b>
<b>Patients Served</b>	Patients of any age, at any stage of advanced and life-threatening illness.	Dying patients of any age.
<b>Services Provided</b>	<ul style="list-style-type: none"> <li>• Throughout illness and simultaneous with other treatment.</li> <li>• Comprehensive, coordinated pain and symptom control.</li> <li>• Care of psychological and spiritual needs.</li> <li>• Family support and assistance in making transitions between care settings.</li> </ul>	<ul style="list-style-type: none"> <li>• At the end of life and when curative treatment not desired or not effective.</li> <li>• Comprehensive, coordinated pain and symptom control.</li> <li>• Care of psychological and spiritual needs.</li> <li>• Family support and assistance in making transitions between care settings.</li> <li>• Bereavement care for survivors.</li> </ul>
<b>Key Differences</b>	<ul style="list-style-type: none"> <li>• Program open to all seriously ill patients, not just those with six-month prognosis.</li> <li>• Patients do not have to forgo curative care.</li> </ul>	<ul style="list-style-type: none"> <li>• Usually patient has a six-month prognosis.</li> <li>• Efforts to cure or prolong life are not covered.</li> </ul>

Retrieved March 6, 2008, from <http://www.capc.org/building-a-hospital-based-palliative-care-program/case/definingpc>



## **APPENDIX 28: List of Online Resources**

### **Canada:**

Canadian Hospice Palliative Care Association

<http://www.chpca.net/home.htm>

Canadian Virtual Hospice

<http://www.virtualhospice.ca/>

Centre for Education and Research on Aging & Health – Lakehead University

<http://cerah.lakeheadu.ca/>

Edmonton Regional Palliative Care Program

<http://www.palliative.org/index.htm>

Government of Alberta – Lakeland Regional Health Authority’s Integrated Community-Based Palliative Care Program

[http://www.health.gov.ab.ca/key/phc\\_palliative12.pdf](http://www.health.gov.ab.ca/key/phc_palliative12.pdf)

[http://www.health.gov.ab.ca/key/phc\\_palliativeindependent12.pdf](http://www.health.gov.ab.ca/key/phc_palliativeindependent12.pdf)

Government of British Columbia – Framework for End-of-Life Care

<http://www.healthservices.gov.bc.ca/hcc/endoflife.html>

Government of British Columbia – Joint Protocol for Expected Home Death

[http://www.healthservices.gov.bc.ca/hcc/pdf/expected\\_home\\_death.pdf](http://www.healthservices.gov.bc.ca/hcc/pdf/expected_home_death.pdf)

Office of the Information and Privacy Commissioner for Ontario

[www.ipc.on.ca](http://www.ipc.on.ca)

Palliative Care Integration Project – Queen’s University

<http://meds.queensu.ca/~palcare/PCIP/PCIPHome.html>

Rural Palliative Home Care Project – Nova Scotia & PEI

<http://www.gov.ns.ca/health/downloads/Palliative%20Care.pdf>

South West End-of-Life Care Network

<http://www.thehealthline.ca/PalliativeCare/>

Temmy Latner Centre for Palliative Care – Hospice Palliative Care Network Project

<http://www.tlcpc.org/hpcnet/index.php>

**U.S.A.:**

Centre to Advance Palliative Care

<http://www.capc.org/>

End of Life / Palliative Education Resource Centre

<http://www.eperc.mcw.edu/About.htm>

National Rural Health Association – Providing Hospice and Palliative Care in Rural and Frontier Areas: A Technical Assistance Toolkit

[http://www.nrharural.org/pubs/pdf/Rural\\_Toolkit.pdf](http://www.nrharural.org/pubs/pdf/Rural_Toolkit.pdf)

Promoting Excellence in End-of-Life Care

<http://www.promotingexcellence.org/i4a/pages/index.cfm?pageid=1>

**International:**

Australia's Rural Palliative Care Program (excellent Resource Kit)

<http://www.agpn.com.au/site/index.cfm?display=683>

interRAI – the collaborative network of researchers who have developed several assessment tools, including the RAI-PC

[www.interrai.org](http://www.interrai.org)

## APPENDIX B – Dr. Mary Lou Kelley’s Model

### DEVELOPING RURAL PALLIATIVE CARE: A CONCEPTUAL MODEL

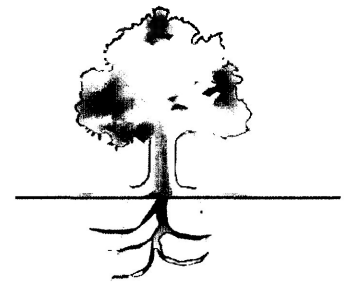
The model was developed by Dr. Mary Lou Kelley based on data collected from rural health care providers who work in six rural and remote areas of Canada. It uses the organic metaphor of a tree to represent developing rural palliative care.

The model outlines **four phases** in developing palliative care in a rural community. The phases outline a dynamic, sequential, but gradual transformative process over time. Each one includes a number of activities or processes that grow out of and build upon those of the previous phase; however, work in all phases is ongoing (it has no end). The overarching keys to success for developing rural palliative care are working together, and staying community-focused.

#### **Phase 1: Antecedent Community Conditions**

In the model, four antecedent conditions form the basis for community development; these conditions must preexist if development is to be successful. The conditions are:

- having sufficient local health care infrastructure (services, providers, resources)
- having an approach to health care practice that is collaborative and generalist, where providers having multiple roles, and their personal and professional relationships overlap
- having a vision to improve care of dying people
- having a sense of community control/empowerment



The keys to successful development in this phase include working in a small community, working together, and being community-focused.

#### **Phase 2: Experiencing a Catalyst**

A catalyst for change occurs in the community, disrupting their current approach to caring for dying people. This catalyst can be a person (e.g. a local champion) or an event such as a “bad death”, funding or education.

#### **Phase 3: Creating a Community Palliative Care Team**

Generalist providers join together to collectively improve community care of the dying and develop “palliative care”. Major themes include: having dedicated providers and getting the right people involved. Keys to success in this phase include: working together (strong relationships, communication, support), dedication, and physician involvement.

#### **Phase 4: Growing the Palliative Care Program**

The team continues to build, but now is ready to extend into the community to deliver palliative care. Major themes include: strengthening the team, engaging the community, sustaining palliative care. The team is strengthened through sharing their knowledge and skills amongst themselves, and creating linkages with experts outside the community. Local team members build their confidence for providing palliative care. Teams now begin to change clinical practice, educating and supporting local health care providers, and building community relationships to improve service delivery. Team efforts evolve to include managing challenges, getting additional resources and developing policies needed to sustain the new program. The keys to team success for growing the program were: remaining community focused; educating community providers; working together/teamwork; having local leadership and feeling pride in their accomplishments.

**APPENDIX C – Memo to Research Ethics Board adding Hilary Mettam onto project**



Centre for Education and Research on Aging & Health

Tel. (807) 766-7271

Fax (807) 766-7222

Email [dlamers@lakeheadu.ca](mailto:dlamers@lakeheadu.ca)

**MEMORANDUM**

**Date:** October 27, 2008

**To:** Dr. Richard Maundrell

**From:** Dr. Mary Lou Kelley

**Subject:** Adding Research Assistants for the approved 'Developing Rural Palliative Care: Evaluating a Conceptual Model' project

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**Please be advised that we would like to add two graduate students (Hilary Mettam and Alesha Gaudet) as Research Assistants for the project entitled "Developing Rural Palliative Care: Evaluating a Conceptual Model", which has been approved by the REB. Hilary and Alesha will be aiding researchers with data collection and analysis of the focus groups and interviews. Attached please find the ethics approval form from the REB, as well as the Certificate of Completion from the TCPS for both of the RAs.**

**Thank you.**

**Dr. Mary Lou Kelley**

APPENDIX D – Hilary Mettam’s Tri-Council Ethics Certificate

*Certificate of Completion*

*This is to certify that*

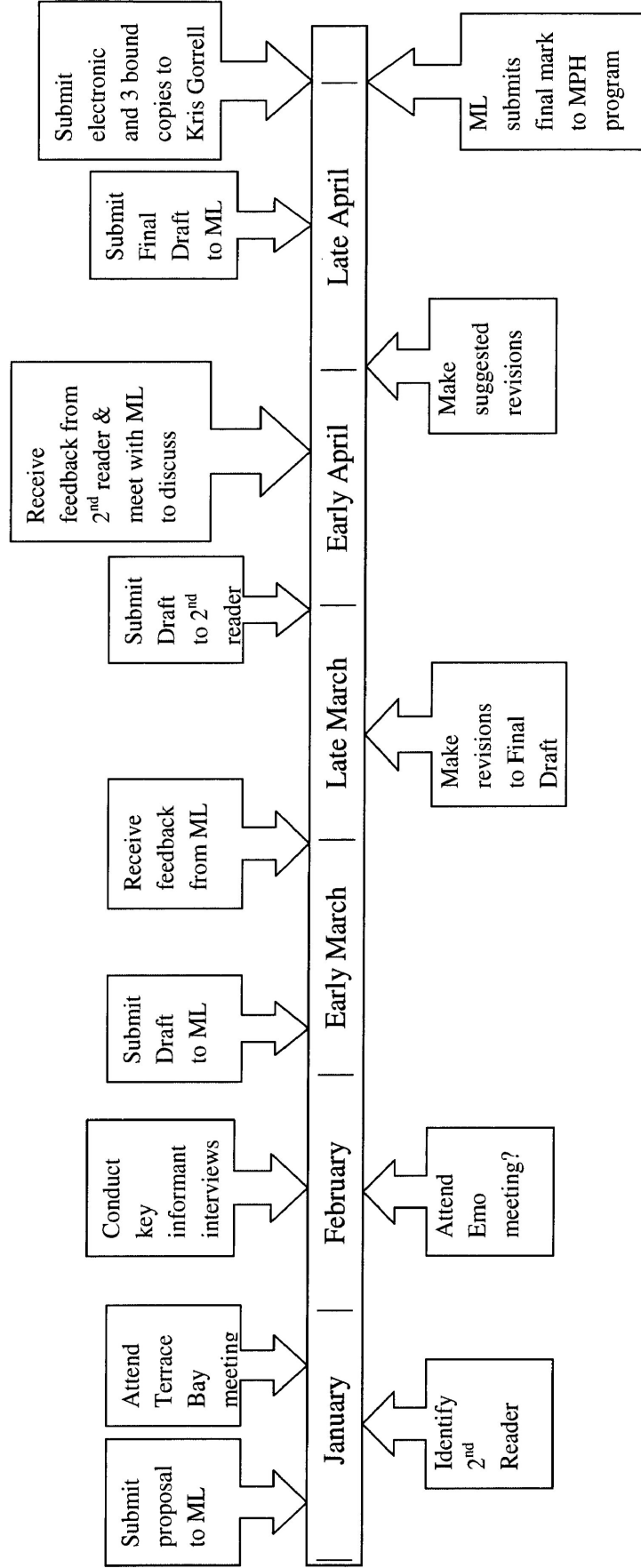
**Hilary Mettam**

---

*has completed the Interagency Advisory Panel on Research Ethics'  
Introductory Tutorial for the  
Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS)*

*Issued On:* October 22, 2008

**APPENDIX E – PROJECT TIMELINE**



**APPENDIX F – Interview Guide – Emo****Use:**

1. How has your team used the Toolkit?
  - to help structure your team?
  - to help develop clinical processes?

**Content:**

1. What sections were the most useful?
2. What changes would you make to the Toolkit? What changes have you made?
  - any improvements that could make it more valuable to communities?
3. What is missing from the Toolkit that could enhance it?
  - can you think of any other resources that should be added to it?
  - has your community developed any other documents or tools that could be included in a revised Toolkit?
  - has your community accessed or used other resources that aren't in the Toolkit?
4. How have the contents of the Toolkit been applicable to your work?
  - what forms/documents from the Toolkit have you used the most?
  - what pieces of the Toolkit have been put into practice?

**Utility/Usefulness:**

1. How “user-friendly” is the Toolkit?
  - what changes to layout/format could be made to make it more user-friendly?
  - what format (electronic/hard copy) should the Toolkit be presented in?
2. How has the Toolkit contributed to the development of your palliative care program?
  - how has the Toolkit assisted you in implementing your program?
3. How would you recommend other communities use it?
4. At what point in a program's development should it be introduced?

## APPENDIX G – Interview Guide – Terrace Bay/Schreiber

### Use:

2. What were your first impressions of the Toolkit?
3. How has your team used the Toolkit?
  - to help structure your team?
  - to help develop clinical processes?
4. When you first received the Toolkit, how did you disseminate it or share it amongst the team?
5. What pieces did you zero in on first?
  - what parts of the Toolkit did you use first?

### Content:

1. What did you like best about this Toolkit?
  - what sections were the most useful?
2. What changes would you make to the Toolkit?
  - any improvements that could make it more valuable to communities?
3. What was missing from the Toolkit that could enhance it?
  - can you think of any other resources that should be added to it?
  - has your community developed any other documents or tools that could be included in a revised Toolkit?
  - has your community accessed or used other resources that aren't in the Toolkit?
4. How were the contents of the Toolkit applicable to your work?
  - how was the information contained in the Toolkit relevant to your community/your team?

### Utility/Usefulness:

5. How was the Toolkit useful to you?
6. How “user-friendly” was the Toolkit?
  - what changes to layout/format could be made to make it more user-friendly?
  - what format (electronic/hard copy) should the Toolkit be presented in?
7. How did the Toolkit contribute to the development of your palliative care program?
  - how did the Toolkit help to move along the development of your program?
  - how did the Toolkit affect your team's progress in developing a palliative care program?
4. How would you recommend other communities use it?
5. At what point in a program's development should it be introduced?



## **APPENDIX H – Interview Guide – EOL Coordinator**

### Dissemination of Toolkit:

1. How has the Toolkit been disseminated so far?
  - Which communities have received the Toolkit?
2. At what point in a community's development are you introducing the Toolkit?
  - How are you introducing it?
3. How is the Toolkit being disseminated within communities? (e.g. How is the Toolkit being shared between team members?)

### Use of Toolkit:

1. How is the Toolkit being used by communities?
  - How are you advising communities on using the Toolkit?
2. What parts of the Toolkit are communities using first?
  - What pieces do they seem to zero in on? Why?
3. How has the Toolkit advanced communities' program development?
  - How has the Toolkit been helpful to communities?
4. What have been communities' responses to the Toolkit so far?

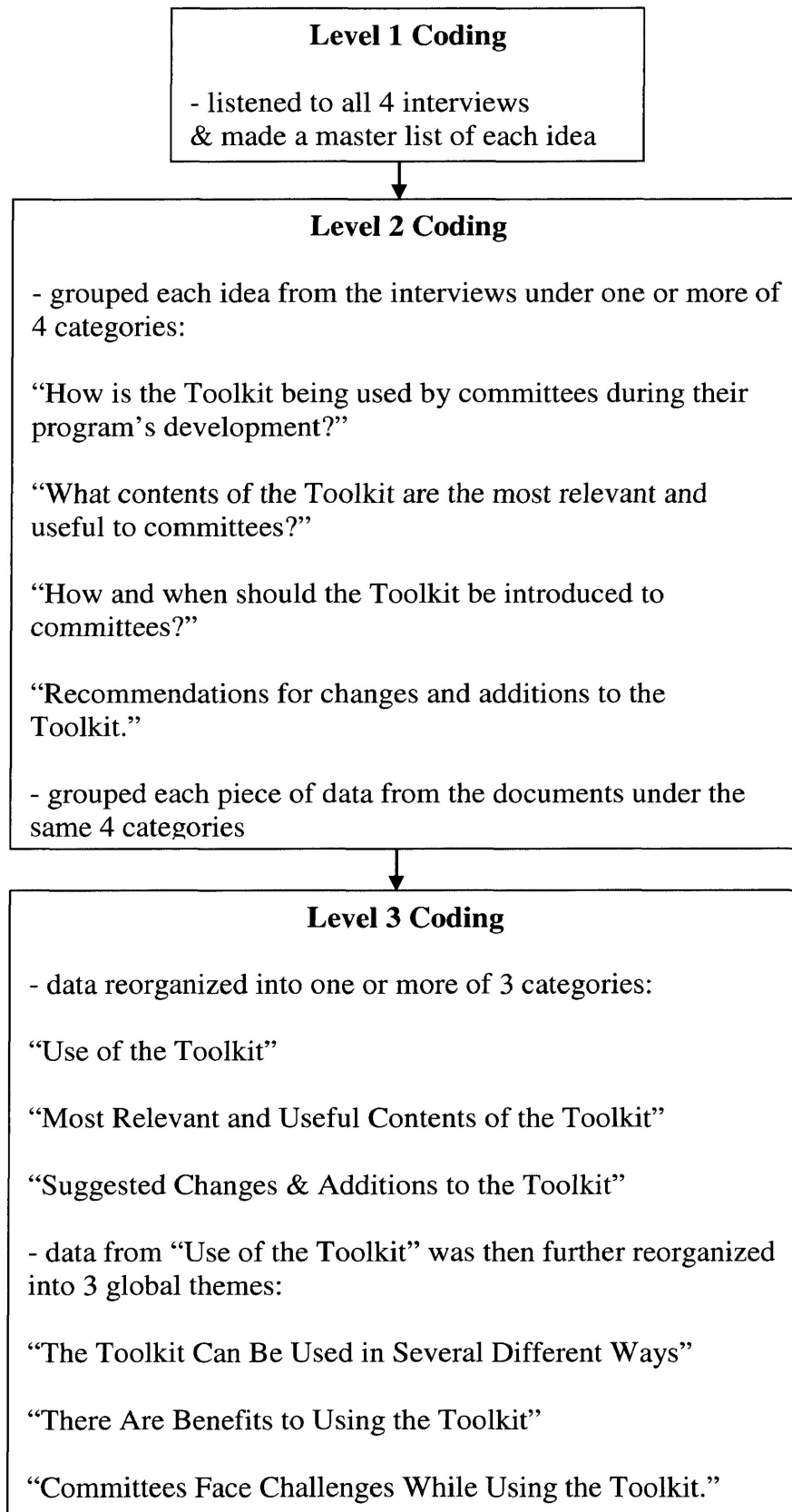
### Content of Toolkit:

1. What do you feel are the most important components of the Toolkit?
2. What changes have been made to the Toolkit since last Spring?
  - what has been added to it?
3. What is Emo still working on with regards to the Toolkit?
  - Describe the ongoing work on the Toolkit.

### Possible Changes/Additions to Toolkit:

1. What is still missing from the Toolkit that would be beneficial to communities?
  - what are the biggest roadblocks that communities face when developing their program?
  - what could be added to the Toolkit to help communities overcome these roadblocks?
2. What documents or processes being created by other communities could be added to the Toolkit?
3. What feedback or suggestions have you had from communities re. improving the Toolkit?
4. How do you see the Toolkit evolving?
5. How should an updated Toolkit be disseminated?

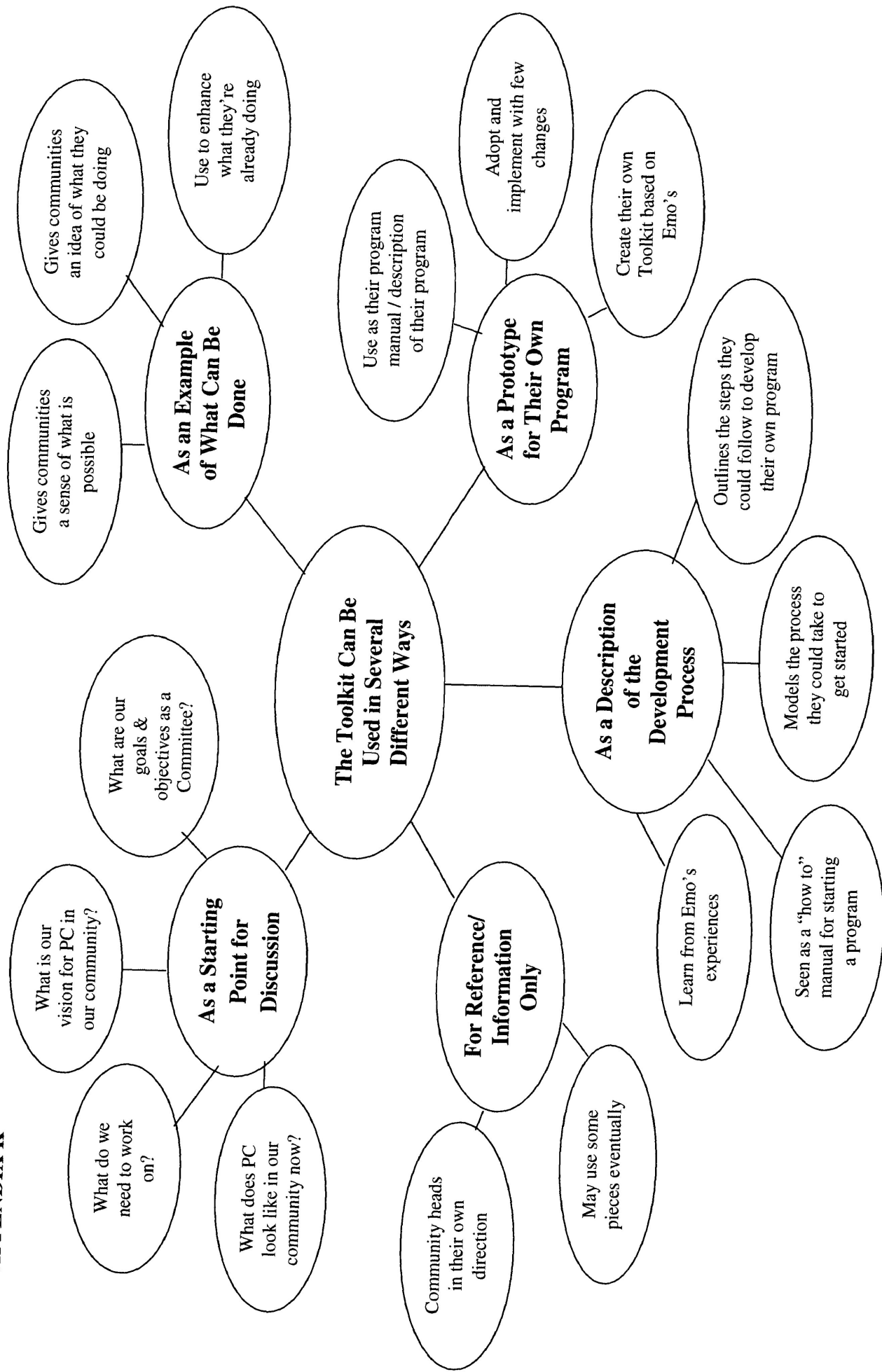
**APPENDIX I – Data Analysis Process**



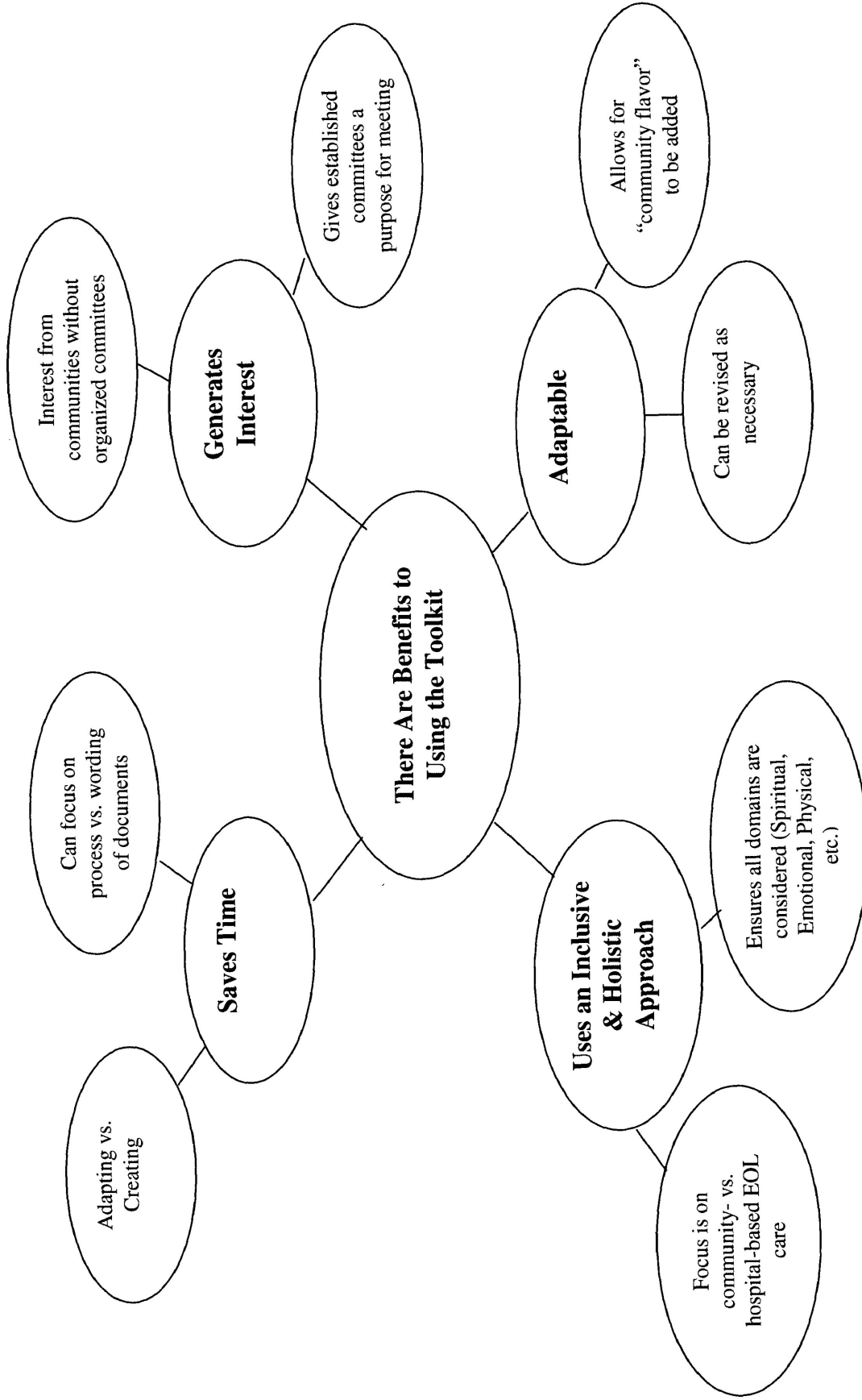
**APPENDIX J: Dissemination of Toolkit in Northwestern Ontario**

Community	Received Toolkit?	Action Taken
Atikokan	Yes	Family Health Team & CCAC have looked at Path of Care; has not been disseminated to entire committee yet
Dryden	Yes	Approaching it as "information only"; Tackling their own "to do" list instead
Emo	Yes	Starting to put components of it into practice
Fort Frances	Yes	Chair has looked through it but haven't discussed it as a committee yet
Geraldton-Longlac	No	Do not have a team/committee
Kenora	No	Offered, but haven't asked for copies yet
Manitouwadge	Yes	Don't have a team or committee yet but Toolkit given to interested individuals in the community (e.g. nurses)
Marathon	Yes	Discussed it as a committee; started work on the pamphlet and Path of Care
Nipigon-Red Rock	No	Do not have a team/committee
Rainy River	Yes	Discussed it as a committee; will use as a prototype for developing their own Toolkit
Red Lake-Ear Falls	Yes	Working on their Path of Care
Sioux Lookout	?	May have received a copy; not ready to do anything with it yet
Terrace Bay-Schreiber	Yes	Discussed it as a committee; started work on the pamphlet and Path of Care

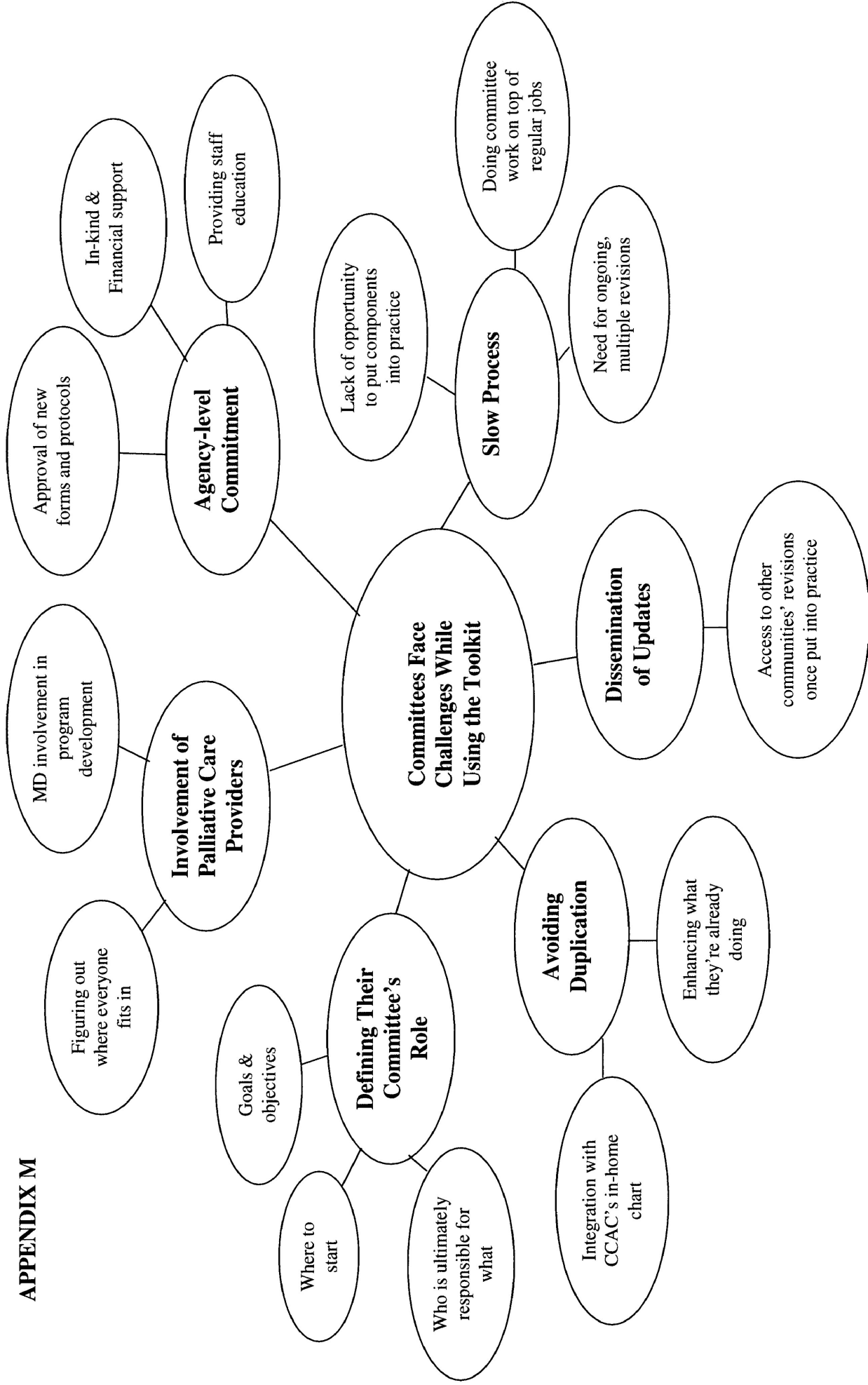
**APPENDIX K**



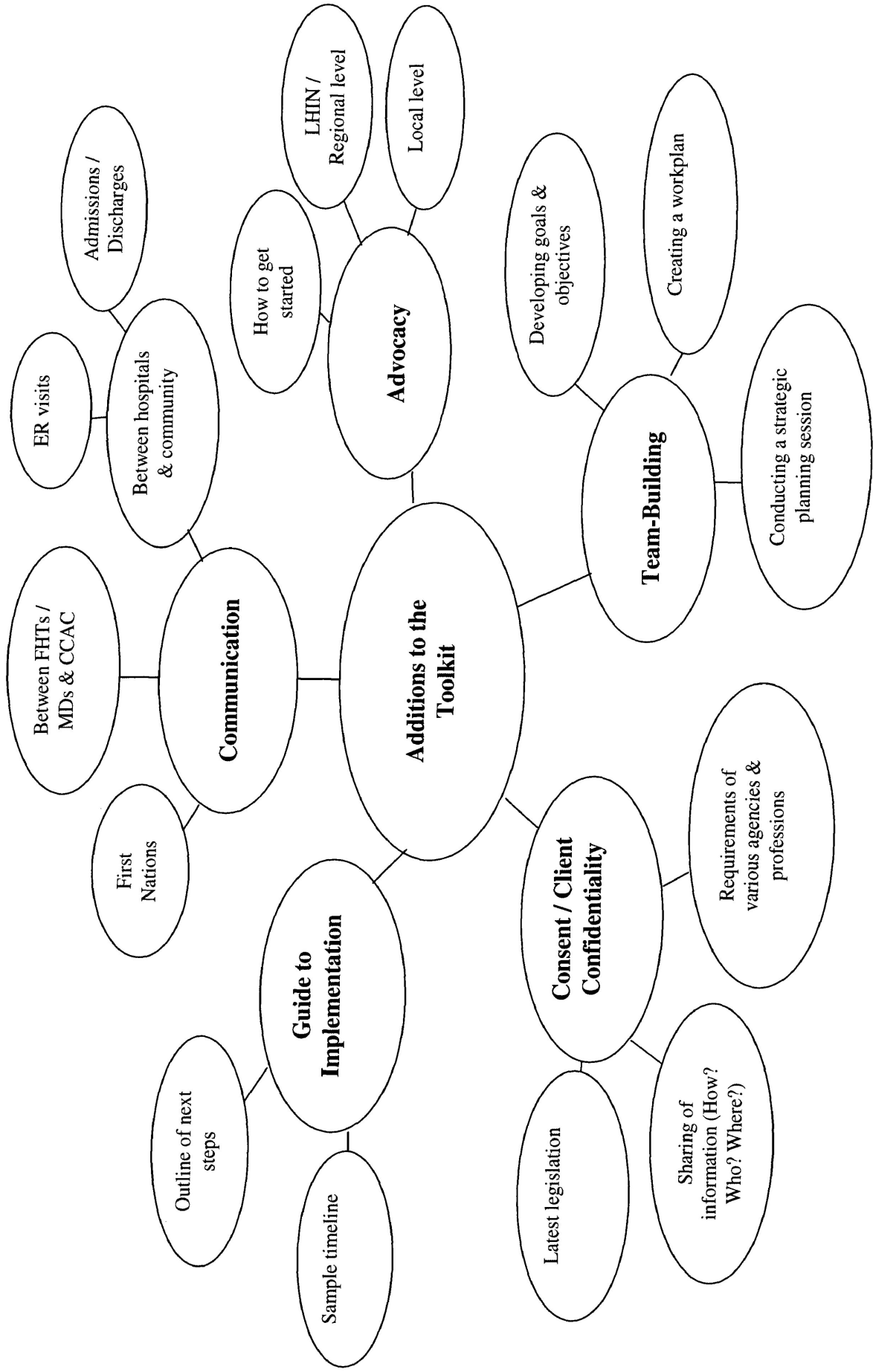
# APPENDIX L



**APPENDIX M**



**APPENDIX N**



## APPENDIX O – Documents to be Added to the Toolkit

### General:

- template for submitting information to 211ontarionorth.ca
- official government form that is filled out for Expected Death in the Home
- different intake and assessment forms (e.g. forms used by First Nations agencies)
- different examples of Paths of Care as they are developed by communities (e.g. one that incorporates a Family Health Team; one that incorporates First Nations)

### Currently in development by specific communities:

- Emo***
- ER “report back” form between Fort Frances Hospital & Emo
  - a description of their purple wristband initiative to help i.d. PC clients being admitted to hospital
  - revised intake form
  - letter of invitation for First Nations representatives to join the committee
  - expanded Terms of Reference with goals & objectives section added
  - a description of the palliative care rounds now taking place at the hospital
- Terrace Bay***
- a description of the education session they are holding for local health care providers (hospital admins., staff nurses, MDs) & any handouts they develop for this session
  - locum orientation package
  - revised Flow Chart (less MD-directed)
- Atikokan***
- “report back” form between Family Health Team & CCAC case manager
- Fort Frances***
- set of standing orders for medical care of palliative clients in both the community and long-term care
- Red Lake***
- presentation to their Medical Advisory Committee
- Rainy River***
- letter sent to Riverside Counselling regarding the importance of the counselor position to palliative care (as an example of advocacy at the local level)