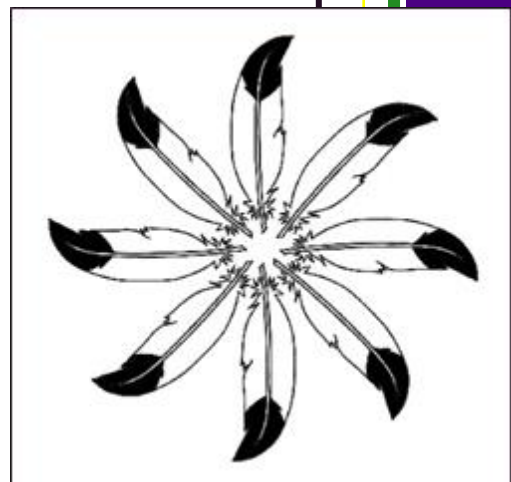


**Detailing the Evolution of
Palliative Care in Peguis First
Nation: Creating a Timeline**

August 2011



Historical Provision of End-of-Life Care

Prior to the Home and Community Care program's inception 11 years ago, the Percy E. Moore hospital was the only provider of end-of-life care/ Palliative care. Other than the Percy E Moore Hospital there is the Peguis Senior Centre which provides care in the community to the elderly, it was stated in a previous interview with the acting Nurse in Charge Geraldine Heinrichs that space was initially available to provide temporary respite care to help the families who were providing care such as palliative care to their loved ones at home, unfortunately this space could not be further designated as temporary as it remained occupied for full time care. Historically there were no formally funded home care programs in place which resulted in no monies available to assist in any home care programming. Those that were involved in EOL/Palliative care formally was Percy E Moore hospital if there were able to accommodate patients' needs, if not the patient was required to stay in medical facilities outside of the community, i.e. Winnipeg hospitals. Informally, there was no directly identifiable facility that provided EOL/Palliative care. Fortunately there were community members in and around the various Winnipeg hospitals and Percy E Moore hospital that were of assistance on a limited basis. These community members were individuals who volunteered their time to assist the families when they were experiencing medical crisis. The members were normally off duty nurses, friends of the family or relatives of the family. These volunteers often assisted with such tasks such as providing lunches, assisting with the communication with other family members, notifying the family clergy and most importantly just offering to sit with either family or patient.

The key leadership in end-of-life care development within the Peguis First Nation was a combined effort of individuals or departments; such as: Jeroline Smith; Home and Community Care Program Manager, Peguis Chief & Council and the Peguis Health Centre. For example, Jeroline currently offers and teaches the Friends & Hands course. This Friends in Hand course is a portable 20 hour volunteer education program taught by Palliative care professionals representing chaplaincy, nursing, medicine, social work and volunteer management. In addition, Jeroline currently provides instruction on End-of-Life Care within the community. Jeroline has also contributed her expertise to the manual on National development of Palliative Care. She has dedicated and volunteered her time to provide care to those who are in need of her health care proficiency. |As for the other partners, Chief and Council and the Health Administrator; Mrs. Doris Bear has dedicated their willingness and desire to develop Palliative/End-of-Life care within the community by eagerly and whole heartedly consenting and assisting Lakehead University with Participatory Action research focused on improving End-of-Life care in First Nations communities , more so specifically within Peguis First Nation.

The Peguis Home and Community care program came into existence through the First Nation and Inuit Health branch via the 2000 Community Needs Assessment. Initially the services provided were the result of the 2000 community service delivery plan, which lead to front line staff training and eventually involved the process of additional Licensed Practical Nurse & Health care aid training and hiring. The service delivery plan philosophy states "we believe each and every individual has the right to receive appropriate and quality health care and is entitled to receiving appropriate programming related to

improved health.” Peguis Chief and Council place a premium on improving the living conditions for all community members regardless of need and put forth every effort to assist in developing and delivering resources and programming. Peguis Home and Community Care program service delivery plan mission statement “is to provide the highest achievable standard of quality care and services that is holistic and comprehensive in its approach to serving clients and families in their home and community, which will generate and maintain individual independence.” By providing such services, Peguis Home and Community care program expects to significantly decrease the need for institutionalized care of community members.

Partnerships became established between local community and outside agencies as the result of the First Nations and Inuit Health Branch 2000 community services delivery plan. The time line of the agencies becoming involved in End-of-Life care in the community occurs on the onset of the client’s diagnosis of illness. This process is normally initiated on behalf of an enquiring family member but is frequently as a result of a referral from a health care professional from Winnipeg, Interlake Regional Health, or Percy E Moore Hospital. Interlake Regional Health Authority (IRHA) was formed in 1997 under the provincial Regional Health Authority Act with amalgamation of facility based and community based health programs. The IRHA is governed by the Minister of Health who appoints the board of Directors. Under this governing body the Mission of IRHA was produced: “achieve the highest degree of physical, mental, and social well-being of Interlake residents and communities, through publicly funded, and delivered sustainable, accessible integrated health services.” IRHA provides services to 9 First Nation Communities and 12 Non First Nation communities together these communities comprise the North East District

Current Status of Palliative Care in the Community

Funding for palliative care and end-of-life care services are currently nonexistent, no departments in the community receive funding or officially deliver palliative care. This was the foremost contributing reason for Peguis being involved in the current end-of-life/palliative care research project. The resources that are available are provided on a compassionate basis, which eliminates any service overlaps. This deficiency identifies a future that will provide policies, training standards, teaching manuals, resource library, and enough equipment to support more clients (electric beds, overhead tables, blood pressure machines, stethoscopes, thermometers, secure pharmaceutical cupboard, and a storage room to accommodate such equipment).

The current palliative care/end-of-Life care that is available in the community has been provided by the Peguis Home and Community Care program (PCHH), involving partnerships with Winnipeg Regional Health, Interlake Regional Health, and Percy E Moore Hospital. The palliative care services that are deemed essential in the program involves all aspects of Palliative Care. For instance the equipment, resources, training and educational aspects of Palliative Care are deemed essential, without either Palliative care would be futile. Currently the resources in PHCC program are limited, the program manager, Jeroline Smith is able to form and maintain relationships with neighbouring partners i.e. Percy

E. Moore hospital to obtain the specialized service and needed medical equipment. The eligibility requirements for palliative care rest with client needs, referrals, and staff availability. An individual can access palliative care services through hospital referrals or home care referrals from a Physician. Additional supportive services such as counseling, spiritual care, medical equipment and supportive services are provided upon client request on behalf of other available community departments such as Peguis Counseling and Resource centre. These Palliative care services are targeted for the client, family, or those from other community departments who can benefit from the teaching and training of palliative care.

The funding for Palliative Care and End of Life care services are currently nonexistent, there is no department in the community that receives funding or officially delivers palliative care. This leads to the reason for being involved in the current End of Life/Palliative care research today. The funding for limited palliative care is nonexistent, the resources that are available are provided on a compassionate basis, which eliminates any service overlaps. This deficiency identifies a future wish list that will provide policies, training standards, teaching manuals, library resources, and enough equipment to support more than two clients. This includes electric beds, overhead tables, blood pressure machines, stethoscopes, thermometers, secure pharmaceutical cupboard, and a storage room to accommodate such equipment.

Advancing the agenda for the Peguis First Nation and palliative care was made possible by Holly Prince and Jeroline Smith, who met at a Hospice Palliative Care conference in Winnipeg, where Holly was key note speaker. There are several key individuals in the community that worked to advance palliative care in the community, such as the Home and Community Care personnel: Jeroline Smith, Sheryl Kohoko, Donna Spence, Sherri Asham, Denise Spence, Lisa Cook and various spiritual advisors and community Elders. Each individual have dedicated their own expertise in a variety of ways, the commonality of each is related to the health profession and their display of compassion for the community member in need. Presently, there is only one committee that has been established in the community to advance the End of Life/Palliative care agenda. The advisory committee consists of Jeroline Smith; Home and Community Care program manager, Doris Bear; Health Administrator, Maurice Bear; Community Elder, Judy Stevenson; Community Elder and Melissa Manningway; Home and Community Care administrative assistant. This advisory committee converges to provide support and guidance to the Aboriginal Community Facilitator, who is leading the research within the community. The Aboriginal Community Facilitator is the catalyst for obtaining valuable information from the community and health care providers in attempts to gain additional resources necessary to implement End of Life/ Palliative care programming.

In attempts to advance EOL Palliative care programming within the community, every effort to support and adhere to the research process has been embraced by such decision makers such, as Chief and Council, who have been entrusted by the community to oversee the needs in relation to essential programming and funding. The community of Peguis First nation has a large membership and has progressively demonstrated the need and desire to die with dignity within their homes in the

community as, recognized by the current leadership. Chief and Council are receptive of this by allowing research to progress and facilitate positive change within the community. There are a number of partnerships involved in seeking support to advance End of Life / Palliative care programming within the Peguis First Nation. First and foremost the momentous partnership with Lakehead University, for selecting our community to participate in the research process in unification with four other communities: Fort William First Nation, Naothkamegwanning First Nation, and Six Nations. Constructive partnerships with First Nation and Inuit Health are vital to obtain support to facilitate and operate End of Life care/ Palliative care program within the community.

Recent activities within the community have identified a limited awareness of Palliative care; however the consensus of the community identifies the need and desire to die at home. The educational component of palliative care has been provided to Home and Community Care staff and a few community members via the Manitoba Palliative Care Friend in Hand course, which was purchased and instructed by Jeroline Smith. The Friends in Hand program represents chaplaincy, nursing, medicine, social work, and volunteer management based on a portable volunteer education program. Unfortunately, due to the limited resources and scheduling of personnel there is limited educational resources provided on Palliative care available in the community. There was additional access to education provided on behalf of St. Elizabeth First Nations, Inuit and Metis Program and Pallium Project. Individuals have access to Palliative Care information via information sessions supported by Manitoba Hospice, who visited in the community, presenting at health fairs, and setting up information booths. A combination of the education available and the community need and awareness is actually related to the words and desire to die at home as stated by many community members and staff at Peguis Senior Home.

Regarding program accountability, there is no current End-of-Life/Palliative care program established within the community. Alternate programming such as Home and Community Care provides limited Palliative care services due to the limited resources and funding available. Home and Community Care is able to provide palliative care services based on available personnel and equipment. Any Palliative care services previously provided have no official documentation, any current documenting occurs within the client's chart that are maintained within the Home and Community Care program. Through the Lakehead research project, access to funding may become available as the project progresses to support activities that are progressing in the community today. It is through this process the community desires to achieve and maintain programming and funding on a continual basis.

There are many valuable partnerships for the community of Peguis First Nation. Currently, partnerships exist between Home & Community Care, Lakehead University, Percy E. Moore hospital, Winnipeg Regional Health, Health Science centre, Cancer Care, Manitoba Hospice, St Elizabeth health care, and Peguis Senior Centre. The structure of each partnership may vary from one another but the ideal goal is a collaboration of supports to benefit the needs of the client and their family. These relationships have developed mainly through community needs, outreach programs, conferences, and meetings with key informants.

Currently there is no external agency that provides home care to the community. Peguis First Nation operates the Home & Community Care within the community which was achieved via the community service delivery plan and needs assessment presented to and approved by First Nation Inuit Health branch. The Home and Community care program is administered on a need basis; if the client is referred from any one of the partnerships the care/ program resources are made available. The resources that can be accessed through these partners are often in the form of education, teaching materials, information sessions, and pamphlets. While resources are available on a weekly basis; unfortunately no funding is available to address the needs on a continual basis.

The Future of Palliative Care

The future goals of the community in terms of being involved in this project; ideally will result in establishing policies, standards and funding to implement palliative care in the community, to support and educate the community membership under the expertise of qualified palliative care provider and/or team. In 5-10 years, the vision for palliative care will entail full implementation of the project that will address the education and funding deficiencies. This will remove the current community perception associated with death and dying, resulting in awareness and acknowledgement of palliative care and End-of-Life care.

Methodology

The information used to create the historical timeline was supplied by interviews with several key informants and through documents and websites. Key informants were interviewed on several occasions to provide insight into the history and current status of Palliative/End-of-Life care in Peguis First Nation. In order to assist the Community Facilitator in ensuring key questions were asked, a Historical timeline interview guide tool was created by the research team and implemented in community interviews. Key informants supplied valuable information regarding the history of health care services in Peguis; evolution and current status of Peguis Home and Community Care; palliative care education, training, and access to medical supplies and equipment; staff training and educational needs; and important documentation, resources, literature and websites.

Key Interviews are as follows: Jeroline Smith was the dominant participant in providing insight on the time line as she was contacted seven times and provided constructive information on every aspect of the time line questions. Sheryl Kohoko was contacted at least twice in regards to providing information on her employment experience with Peguis Home and Community Care. Denise Spence was contacted on three separate occasions which provided insight on her experience with palliative care education, training and needed equipment. Melissa Manningway was contacted at least five times and provided reference to websites and literature available in regards to end of life / palliative care. Geraldine Heinrichs was contacted twice in regards to community and staff training and education.

Resources:

Peguis First Nation website

Friends in Hand website

St. Elizabeth website

Interlake Regional Health Authority Website

Peguis First Nation Service Delivery Plan